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# Unbearable Fruit: Black Women's Experiences with Uterine Fibroids

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# UNBEARABLE FRUIT: BLACK WOMEN'S EXPERIENCES WITH UTERINE FIBROIDS

by

RANEL L. MYLES

Under the Direction of Adia Harvey Wingfield

## ABSTRACT

Uterine Fibroids, medically termed uterine leiomyoma, are benign tumors of smooth muscle cells that grow in the uterus. While they are the most common pelvic neoplasm in women and fewer than 1 percent of fibroids develop into cancer, uterine fibroids can cause infertility, adverse pregnancy outcomes, and greatly affect one's quality of life. Black women have been disproportionately affected by fibroids; when compared to white women, Black women are: 2-3 times more likely to have fibroids, diagnosed at a younger age, more likely to have 7 or more fibroids, more likely to have more severe and more troublesome symptoms (anemia, severe pelvic pain, constipation, and stomach aches), and have twice as many hysterectomies due to fibroids. Black women's disproportionate affliction with uterine fibroids is particularly concerning given the historical medical injustices associated with Black women's bodies and reproductive rights from slavery to present day. By placing Black women at the center of analysis and using a Black feminist epistemological framework, this study aims to make a unique contribution to medical sociology as well as literature on the theoretical and practical management of

sickness and wellness among Black women in the United States. Using qualitative interviews and grounded theory methodology, the study examined how Black women frame the condition of having uterine fibroids. Specifically, the study investigated a) how Black women conceptualize having fibroids, b) how Black women's conceptualizations of fibroids affect their feelings about selves or their lifestyles, c) the mechanisms, if any, by which Black women deal with uterine fibroids, d) how their multiple race, class, and gender identities affect their illness experiences and types of treatment that they seek, and e) how conventional and complementary/alternative medicine shapes Black women's experiences with fibroids. Conceptualizations about fibroids are rooted in the race-gendered histories of Black women and the unique stressors that they face. Through interactions with doctors and among peers, Black women resist the unbearable burden of uterine fibroids through various coping strategies, but generally "keep it moving". They avoid invasive surgeries through patient agency by being advocates for their medical treatment, self-researching, dialoguing with others, and directing doctor-patient interactions.

**INDEX WORDS:** Uterine fibroids, Uterine leiomyoma, Black women, Black feminist epistemology, Patient agency, Doctor-patient relationship, Fibroid impact on fertility

UNBEARABLE FRUIT: BLACK WOMEN'S EXPERIENCES WITH UTERINE FIBROIDS

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RANEL L. MYLES

A Dissertation Submitted in Partial Fulfillment of the Requirements for the Degree of

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2013



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### **DEDICATION**

This dissertation is dedicated to all the lovely, phenomenal, and strong Black women in this study who willingly shared their experiences with me; it is also dedicated to all women who suffer from uterine fibroids whose voices are not often heard, and whose experiences are misunderstood and minimized.

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## CHAPTER 1: INTRODUCTION

### PURPOSE OF THE STUDY

The purpose of this study is to examine Black women's social and personal experiences with uterine fibroids, an adverse health condition that predominantly affects Black women. The study examines how the intersections of race, class, and gender impact Black women's experiences with uterine fibroids in the United States. The study also explores how conventional and complementary/alternative medicine affect the way Black women cope with and/or respond to uterine fibroids. By placing Black women at the center of analysis and using a Black Feminist epistemology, this qualitative study contributes a unique perspective to the sociology of medicine as well as the theoretical and practical management of sickness and wellness among Black women in the US.

Research on racial health disparities has received a great deal of attention in academia and health-related fields. For example, for nearly every disease or condition from heart disease to diabetes, Blacks suffer from the highest rates of morbidity. Black men continue to have the lowest life-expectancy rate, and infant mortality is highest among Black mothers (National Center for Health Statistics 2010; Office of Minority Health and Health Disparities 2012). While efforts have been made to understand or address these racial disparities in health, analyses have not always taken an intersectional approach to understanding the racialized gender dynamics of health. It is important to understand how health disparities, patient responses to them, and decisions about treatment may be specifically raced *and* gendered, and this is lacking in health-related research. There are few health-related studies that take into account the unique position of being both Black and female and how health is impacted by this status, or how this status impacts interactions with the healthcare system. Previous qualitative research has failed to adequately capture how Black women cope with or respond to particularly racialized and gendered medical conditions by which they are disproportionately affected. Uterine fibroids, which predominantly affect Black women, offers a way to examine Black women's health narratives.

Uterine fibroids are benign tumors that grow in the uterus. Black women are 2-3 times more likely than women of all other races to have fibroids; are more likely to have larger and multiple fibroids; to suffer from more severe symptoms; to develop fibroids and symptoms at a younger age; and to have more hysterectomies than white women. Black women are impacted the most by this condition (Kjerulff et al. 1996; Schwartz and Marshall 2000; Wise, Stewart, and Rosenberg 2005). The present study addresses the overarching question: “How do Black women frame the condition of having uterine fibroids?” Thus, I investigate a) how Black women conceptualize having fibroids, b) whether Black women’s conceptualizations of fibroids affect feelings about selves or their lifestyles, c) the mechanisms, if any, by which Black women deal with uterine fibroids, d) whether or how their multiple race, class, and gender identities affect their illness experiences and the types of treatment, if any, that they seek, and e) how conventional and complementary/alternative medicine shapes Black women’s experiences with fibroids.

Furthermore, this study examines the social consequences of illness/medical conditions among an oppressed population whose intersecting identities and realities are often overlooked and misunderstood. Narratives about illness experiences among Black women are relatively absent from medical sociological research, and using a Black Feminist epistemology within a medical sociological framework helps fill this void. These narratives may be useful to medical researchers and health providers regarding fibroid management to Black women, as well as to Black women who suffer from fibroids. The historical exploitation of Black women’s bodies, oftentimes perpetuated by the industry of medicine, may affect how women in this study experience and manage health issues, and how they interact with physicians today. Methodologically, incorporating a qualitative approach to understanding health issues that predominantly affect Black women, such as uterine fibroids, allows for a more productive assessment of the nuances that Black women face as opposed to a quantitative approach.

## PROBLEM STATEMENT

Research has shown that when it comes to Black patients, providers are more verbally dominant, less patient-centered in their communication, generally have a less-positive attitude, and show less concern than they show to white patients (Cooper-Patrick et al. 1999; Gerbert et al. 2003; Johnson et al. 2004; Lori, Yi, and Martyn 2011). Patient satisfaction and the patient-provider relationship are important because they are associated with racial disparities in healthcare. The lower the patient satisfaction and the poorer the patient-provider interaction, the more negative the health outcomes and greater the disparities. Research has found that physicians are more likely to view Black patients as noncompliant with medical advice and less intelligent than whites (Schulman 1999; Smedley, Stith, and Nelson 2003; Van Ryn and Burke 2000). However, it is important to better understand the mechanisms behind “noncompliance.” For some Black women, cultural, financial, institutional factors, and personal beliefs/feelings help explain noncompliance.

As a result of their social positions, racial/ethnic minority women continue to experience health consequences due to variations in medical care, neighborhood contexts, stressors, access to resources, and racism (Williams 2002). Race exacerbates health disparities for Black women, as evidenced by higher mortality rates compared to white women, higher rates of disease, and higher infant mortality rates (Williams 2002). Studies on health disparities in the US have almost always been comparative, using whites as a reference group to measure impact on minority populations. While comparing racial/ethnic minority groups to a racial majority (mainly whites) is important for initially measuring and tracking of health inequities, it is not the most effective way to improve health outcomes among minority populations (Bediako and Griffith 2007). Policies, programs, research agendas, and resources to redress health disparities often overlook the intersecting cultural, economic, gendered, racial, and structural realities of minority populations (Shultz and Mullings 2006). Bediako and Griffith (2007) encourage more emic (or within-group) approaches to reduce health disparities because they tell us

how to intervene instead of just where or what populations need intervention, which is characteristic of etic (comparative) approaches. Diverse perspectives on sickness and wellness are needed to enhance health and ensure health equity across all groups. Research has already revealed that disparities exist among women with uterine fibroids, that Black women experience them differently, and are more likely to have hysterectomies because of fibroids. However, research in this area has not explored in depth how Black women's lives are impacted by fibroids, and how they navigate the healthcare system with regards to fibroid treatment.

There is a dearth of scholarly qualitative research that exclusively examines Black women's experiences with health in general, and even less consider how race and gender impact the ways patients cope with medical conditions. An intersectional approach to investigating Black women's health issues reveals more nuances about their experiences, and makes valuable contributions to medical and sociological research. By analyzing a condition that disproportionately affects Black women, this study applies a Black feminist approach to medical sociology so that Black women are included in the sociological framings of both illness and wellness narratives. Black women's conceptualizations about why fibroids develop are rooted in their experiences as Black women living in the U.S who often contend with the added stress of bearing heavy daily life burdens associated with their race, gender, and sometimes class status. Their experiences with managing fibroids, and how they interact with doctors and medical professionals are also rooted in these experiences and influence how they are treated in the clinical setting. The stories of these Black women's experiences with uterine fibroids have important implications for research about the illness experiences of Black women as well as how clinical interactions might be modified to reduce inequities in the delivery of care and improve the doctor-patient relationships among Black women.

## CHAPTER 2: LITERATURE REVIEW AND THEORETICAL FRAMEWORK

### LITERATURE REVIEW

#### *Black Women and Gynecology*

In order to understand Black women's social and personal experiences with uterine fibroids, it is necessary to consider Black women's history with the medical field. In her book, *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present*, Harriet Washington (2006) provides a thematic historical and contemporary account of issues in medical research about Blacks. In general, Black men and women have been medically exploited in some of the most egregious acts. Some of these acts are well known, like the "Tuskegee Study of Untreated Syphilis in the Negro Male" conducted by the US Public Health Service, where Black men were studied for over 40 years as scientists sought to learn the natural progression of untreated syphilis. Among many unethical actions, one of the most disturbing was that these men were not treated when penicillin became the standard treatment for syphilis 15 years into the study (Jones 1992; Washington 2006). There have also been lesser-known medical mal-treatments such as the experimental radiation injections in human subjects from 1944-1994. Blacks were at greater risk than whites of being injected (Washington 2006). Additionally, controversial social experiments by doctors to reduce births among Black women involved surreptitious sterilization and forced birth control (sometimes experimental birth control) as a requirement for social welfare services (Roberts 1997; Washington 2006). These experiments and experiences with unethical medical researchers, the health care system, physicians, and the government have been brutal for both Black men and women. Particularly, Black women's experiences have been especially oppressive and intrusive as they relate to their health and reproductive rights (Davis 1981; Roberts 1997; Washington 2006; Rosenthal and Lobel 2011).

From slavery to the present, Black women's bodies and reproductive rights have been regulated by forces beyond their control and held in the public eye for society to gawk at and criticize. During



slavery (the 1800's), Black women's bodies were not only used for breeding new slaves for economic profits, but also for the sexual pleasure of the white male slave owners to do with as they pleased (Washington 2006; Roberts 1997). Black women's uteri were subjected to experimental gynecological surgeries without anesthesia or informed consent, as in the case of gynecologist Dr. James Marion Sims (Washington 2006; Roberts 1997). Sims, like many physicians during slavery, bought and bred female slaves explicitly for experimentation in gynecological surgeries. Medical education during that time period left physicians with a lot to learn through practice as opposed to controlled experimental or practical settings. So Sims' justified his surgical experiments on slaves as a way to practice or perfect procedures until they were suitable for use on white women.

For five years (1845-1849), Sims experimented on slave women with vesicovaginal fistulas, which is an abnormal connection between the bladder and vagina that causes continuous urinary leakage into the vagina. These fistulas occur in women who have difficult childbirth or have experienced a sexual trauma such as rape (Washington 2006; MedScape 2012). Sims claimed that his procedures were "not painful enough to justify the trouble and risk attending the administration" of anesthesia, yet years later he conducted the perfected surgery with anesthesia on white women. These women who suffered from multiple incisions, infections, scars, and vaginal tears, had to be forcibly held down on the table in order for Sims to operate (Washington 2006). As an example, one of the slave women, Anarcha, was finally cured of her fistula after five years and more than 30 operations. Although Sims became the "father of American gynecology," rarely has it been discussed or recognized what those Black slave women went through in order for him to gain this prestige.

Sims was not alone in this regard; Dr. Francois Marie Prevost used Black slave women to perfect the cesarean section, and Dr. Ephraim McDowell perfected the ovariectomy (removal of an ovary) on Black slave women (Washington 2006). Other accounts of Black women's reproductive injustices include the story of Saartjie Baartman (The "Hottentot Venus") from what is now South Africa, whose body and

genitalia were put on world display during the 1800's. This unethical, unregulated, and oppressive medical history has led to a disregard for Black female autonomy by physicians and government programs. This has persisted through time as evidenced by the mass sterilization of Black women between 1930 and 1970, and today's disproportionate number of hysterectomies performed on Black women (Roberts 1997; Keshavarz et al. 2002; Washington 2006).

In *Medical Apartheid*, Washington calls attention to the issue of sterilization among Blacks during the eugenics movement of the 1930's during which, "medical social movements placed the sexual behavior and reproduction of Blacks under strict scrutiny and disproportionately forced them into sterility, both temporary and permanent" (Washington 2006:191-192). The mass sterilization of Black women (often against their will) took place over several decades, and in 1973 a class action lawsuit was filed to ban the use of federal funds for sterilization. As a result of that case, it was found that 100,000 to 150,000 poor women in the South had been sterilized annually under federally funded programs, and nearly half of them were Black (Roberts 1997; Washington 2006). Significantly, Washington (2006) mentioned the "Mississippi appendectomy," which was actually a hysterectomy performed on Fannie Lou Hamer, without her consent, when she was treated for what was presumably a uterine fibroid. Mississippi appendectomies happened frequently during this time under the guise of treating other gynecological issues.

Researchers have argued that as a result of the historical medical injustices done to Blacks, they are understandably leery of the medical profession, whether it be clinical trials or seeking medical attention for a health condition (Thorburn and Bogart 2005; Bogart and Thorburn 2006; Washington 2006). Blacks continue to receive substandard care, are less likely to be offered the premier treatment option, and are known to underutilize health services (Agency for Healthcare Research and Quality (AHRQ) 2006; Smedley et al. 2003; Schulman et al. 1999; Chandler 2010). Knowledge of this history of maltreatment and the intergenerational passing of these beliefs has implications for health-seeking

behavior, medical decisions, and health disparities for a variety of conditions (Rosenthal and Lobel 2011; Chandler 2010). The qualitative experiences of Black women have been overlooked because much of the research in the area of medical mistrust and the resulting health-seeking behaviors, has been about Blacks as a whole. This dissertation focuses on Black women to examine how health problems to which they are disproportionately subjected are interpreted, conceptualized, and treated in the medical field.

### *The Need for Black Feminist Epistemology*

Due to Black women's simultaneous identities of being Black and female, Black women are subject to distinct forms of oppression. They experience gendered racism where they not only are exposed to the sexism that white women may experience and the racism that Black men may experience, but also the combination of both which creates a wholly unique experience. Black women have reported being discriminated against in the workplace, educational settings, being mistreated by law enforcement, and being distressed from exposure to negative images in the media and patronizing attitudes from others (Essed 1991; Jones and Shorter-Gooden 2003). This gendered racism, the intersecting of both sexism and racism, is associated with high stress, greater psychological distress, and negative health consequences (Essed 1991; Klonoff and Landrine 1995; Klonoff, Landrine, and Ullman 1999; Jackson et al. 2001; Kwate et al. 2003; Thomas, Witherspoon, and Speight 2008). In fact, Thomas, and colleagues (2008) found that perceived gendered racism creates psychological distress among Black women despite the use of coping mechanisms such as avoidance of thought about the experience.

Researchers have also documented the physical effects of racial and gender discrimination on health, particularly for Black women. Geronimus (1992) developed the "weathering" hypothesis in the early 1990's which states that, "the health status of [Black] women may begin to deteriorate in detectable ways in young adulthood as a response to perpetual social and environmental insult or prolonged active coping with stressful circumstances. Such insult may have negative implications for a woman's health or health behaviors" (Geronimus 1996: 590). Among Black mothers in Michigan,

Geronimus found that maternal age is significantly related to increased odds of having a low birth-weight or very low birth-weight infant compared to white women. Additionally, among socioeconomically disadvantaged Black women, health deteriorates more rapidly, and risk factors for poor birth outcomes increase with age (Geronimus 1996). Similarly, experiences of gendered racism are also thought to affect pregnancy outcomes for Black women, particularly giving birth to low birth-weight infants (Collins et al. 2000; Jackson et al. 2001; Rosenthal and Lobel 2011).

Taking into consideration the unique experiences of Black women and their health disparities, it is essential that a Black feminist epistemology serves as the primary theoretical and analytical framework for this dissertation. The impetus for Patricia Hill Collins' (2000) *Black Feminist Thought* arose from the feminist and Black political movements' inability to address the issues of Black women from an intersectional perspective. Because Black women are subjected to gendered racist experiences in everyday life, understanding gendered racial health disparities must come from examining the issues from the *standpoint* of Black women. Black Feminist Thought "specializes in formulating and rearticulating the distinctive, self-defined standpoint" of Black women (Collins 1989: 750). Collins (2000) not only provides an invaluable theoretical framework for the field of sociology with *Black Feminist Thought*, but also an analytical approach using a Black feminist epistemology for scholars to analyze and share the perspectives of Black women on important topics.

Typical positivist methodologies require that the researcher distance him or herself from the research process to achieve objectivity, be devoid of emotions, understand that ethics and values are deemed inappropriate in the research process, and use adversarial debates to ascertain the truth (Collins 2000). However, for Black female researchers, a positivist framework asks Black women to "objectify ourselves, devalue our emotional life, displace our motivations for furthering knowledge about Black women, and confront in an adversarial relationship those with more social economic, and professional power" (Collins 2000: 256). Black Americans are more inclined to engage in therapeutic

medical experimentation (research that might help the participant) as opposed to nontherapeutic experiments (not designed to help the participant) (Washington 2006). Using a Black feminist approach might be seen as a cathartic opportunity for some women and encourage Black women to participate, whereas the positivist approach might deter Black women from participating.

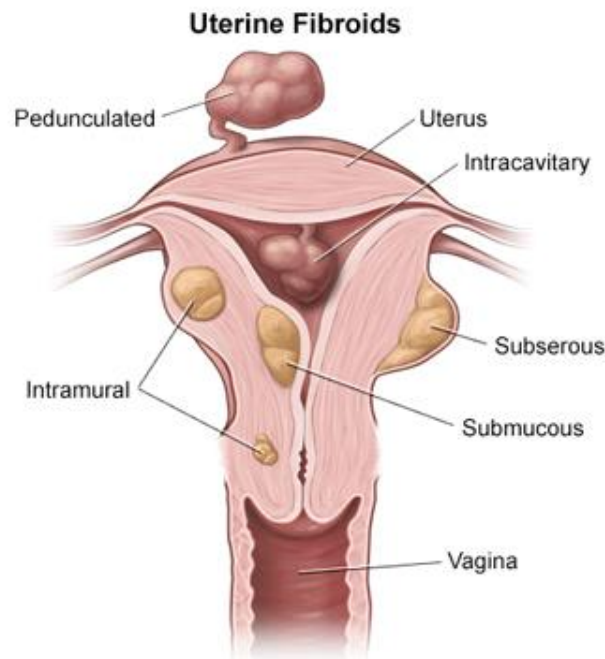
Collins offers Black feminist epistemology as a way to ascertain knowledge in a way that is widely accepted among Black women and that contributes to Black Feminist Thought in many ways. The features of Black feminist epistemology embody: the use of concrete experiences as a criterion of meaning; using dialogue to assess knowledge (connectedness rather than separation); ensuring an ethic of caring (participants are unique, emotions are transparent, and empathy is expressed); and being accountable for knowledge claims that are made (credibility). Uterine fibroids are a prominent gynecological condition that disproportionately affects Black women, and it is important to understand their experiences through a Black feminist lens.

#### *What are Uterine Fibroids?*

Uterine fibroids, medically termed uterine leiomyoma, are benign tumors of smooth muscle cells that grow in the uterus. There is a known relationship between fibroids and estrogen such that fibroid growth is stimulated by increases in estrogen in the body. Therefore, fibroids predominantly grow during the reproductive years and subside after menopause (Miller and Ludovici 1955). Fibroids are the most common pelvic neoplasm in women, where nearly 20-30 percent of reproductive-aged women will experience symptoms (Buttram and Reiter 1981; Kjerulff et al. 1996; Marshall et al. 1998; Boynton-Jarrett et al. 2011).

Fibroids are classified by their location in or outside of the uterus. The Center for Uterine Fibroids offers clear descriptions and illustrations for fibroids and their classifications (see Figure 1). Fibroids are commonly found in, within, and outside the uterine walls. Sometimes they are pedunculated (connected by a tissue to the uterine wall) and hang inside or outside of the uterine cavity

or are sessile (immobile). Ninety-five percent of fibroids are found in the subserosal and intramural locations. Subserosal fibroids are found just beneath the exterior lining of the uterine wall. Intramural fibroids are found within the walls. Submucosal fibroids are found just beneath the interior lining of the uterine walls and can distort the uterine cavity (Bajekal and Li 2000; McLucas 2008; Center for Uterine Fibroids 2011).



**Figure 1. Uterine Fibroids**  
(Center for Uterine Fibroids, 2011)

While the exact etiology of uterine fibroids remains unknown, there are several known risk and protective factors associated with fibroid growth. Black women have a 2-3 times higher risk of fibroids compared to white women, and researchers have been unable to explain this disparity between racial groups (Baird et al. 2003; Marshall et al. 1998). In a case control study of white women, Ross and colleagues found that risk of fibroids decreased with: an increased number of term pregnancies, an increased duration of oral contraceptives, decreased weight, and an increased frequency of cigarette smoking (Ross et al. 1986). Decreased risk with cigarette smoking might seem counterintuitive, and is

potentially due to a spurious relationship between smoking and appetite suppression, which could lead to decreased weight, another factor associated with a decreased risk for fibroids. Women who are physically active were found to have a lower risk of fibroids, after taking into consideration that fibroids might prevent one from exercising (Baird, Dunson, Hill, et al. 2006). Body mass index (BMI) is also associated with an increased fibroid risk, with the highest risk being among overweight women (Terry, De Vivo, Hankinson, et al. 2007).

Recently studies have begun to assess social factors associated with fibroid growth. One study found among white women that the prevalence ratio for those who reported at least one major life event (job loss, major accidents, relationship problems, robbery etc.) compared to those with no events were at higher risk for developing fibroids (Vines, Ta, and Esserman 2010). Fibroids were found to be more prevalent among women who reported sexual and physical abuse during childhood or teen years (Boynton-Jarrett et al. 2011). Nevertheless, despite all of this research there is no clear medical explanation as to why women develop fibroids in the first place, hence the need for more exploration of social determinants.

### *Symptoms and Diagnosis*

Common symptoms associated with uterine fibroids include: menorrhagia (heavy menstrual bleeding), pelvic pain and pressure, enlarged uterus (abdominal protrusion), back pain, bladder pressure (leading to urinary incontinence), and pain during intercourse (Buttram and Reiter 1981; Stewart 2001). While these tumors are typically benign and less than 1 percent of fibroids develop into cancer, they can cause infertility, adverse pregnancy complications, and affect one's quality of life (Stewart 2001; Baird, Dunson, Hill, et al. 2003; Center for Uterine Fibroids 2011). The physician usually diagnoses fibroids during a pelvic exam, initially with a manual uterine palpitation. Other medical tools used in confirmation and evaluation of fibroids include: transvaginal ultrasonography, sonohysterography, hysteroscopy, and magnetic resonance imaging (MRI) (Evans and Brunsell 2007).

### *Infertility, Pregnancy, and Birth Outcomes*

The impact of fibroids on women's reproductive outcomes is dependent upon the location of the fibroids in the uterus. When compared to women without fibroids, women with subserosal fibroids were no different in regards to fertility, pregnancy, or birth outcomes (Klatsky et al. 2008; Pritts, Parker, and Olive 2009). Women with submucosal fibroids, compared to infertile women without fibroids, experienced a significantly lower clinical pregnancy rate, implantation rate, and had a significantly higher spontaneous abortion rate (miscarriage rate) (Klatsky et al. 2008; Pritts et al. 2009). Intramural and submucosal fibroids have similar adverse affects on reproductive outcomes. Women who had submucosal fibroids removed experienced comparable pregnancy rates to women with no fibroids; however removing intramural fibroids yielded no significant differences in pregnancy rates (Klatsky et al. 2008; Pritts et al. 2009; Knox and McClure 2012). Women with uterine fibroids were twice as likely as those without them to have pregnancy complications (first trimester bleeding, abruption placentae, and premature rupture of membranes), complications during labor and delivery (dysfunctional labor, prolonged labor, breech presentation, pre-term delivery, and caesarean section), and were at a higher risk for poor birth outcomes (low birth-weight malformations, and 5-minute Apgar scores of less than 7) (Coronado, Marshall, and Schwartz 2000; Klatsky et al. 2008).

### *Treatment Options*

From 2000-2004, uterine fibroids were the most common reason for hysterectomy, accounting for 40.7 percent of all hysterectomies (Keshavarz et al. 2002; Whiteman et al. 2008). A hysterectomy, the complete removal of the uterus from the body, is the only absolute "cure" for fibroids because the recurrence is impossible without a uterus. While fibroids are the leading indication for hysterectomy in the United States, there are a growing number of treatment options available to women that do not result in sterility and are less invasive (Kjerulff et al. 1996; Keshavarz et al. 2002; Goodwin et. al 2008). These treatment options include: myomectomy, Uterine Fibroid Embolization (UFE), Endometrial



Ablation, hormone therapy, Magnetic Resonance Imaging (MRI) - guided focused ultrasound therapy (MRgFUS), complementary and alternative medicine (CAM), and “wait and see” (Afua 2002; Evans and Brunzell 2007; Center for Uterine Fibroids 2011). Descriptions of the most common treatment options are described briefly below.

An option for women seeking to preserve the uterus and childbearing potential, is the myomectomy. There are three different myomectomy procedures: laparotomy or an open myomectomy, laparoscopic myomectomy, and a hysteroscopic myomectomy. Open myomectomies are the most common myomectomy procedure, and involves an abdominal incision through which the fibroids are cut out of the uterus. A less invasive procedure used for certain subserosal fibroids is the laparoscopic myomectomy, which involves minimal abdominal incision points and the use of a laparoscope and microscopic cameras. Submucosal fibroids can be removed through the vagina using a minimally invasive procedure known as the hysteroscopic myomectomy, which involves a special instrument called a hysteroscope. This technique is primarily useful for women with bleeding or pregnancy-related problems as there is usually little change in the size of the uterus with this approach. Hysteroscopic myomectomies are associated with a lower risk of scar rupture during subsequent pregnancies (Center for Uterine Fibroids 2011).

Uterine Fibroid Embolization is another minimally invasive procedure that uses radiology (x-ray equipment) to block the major blood vessels that flow to the fibroids. First a catheter is inserted into the leg and into the femoral artery. Then, through the use of an x-ray camera (fluoroscope), the physician guides the catheter to the location of the uterine arteries and injects embolic agents (small particles used to stop blood flow through a vessel) to block blood flow to the fibroids. Longitudinal studies have not been completed to determine the long-term effects, so the treatment is not recommended for women who wish to get pregnant later. The MRigFUS allows the physician to use MRI to locate and destroy fibroids without making an incision (Center for Uterine Fibroids 2011). A special MRI scanner

allows the physician to actually visualize the fibroid on a screen and the machine sends a focused, high frequency, high-energy sound wave, which destroys the fibroid(s). The treatment has proven successful with no long-term complications in a 3-year follow-up study (Bajekal and Li 2000; Kim et al. 2011). MRIGFUS was effective in treating a variety of fibroid types, location, and size with positive pregnancy outcomes for women trying to conceive; however, exclusion and inclusion criteria for the procedure are assessed on a case-by-case basis (Abdullah et al. 2010).

Other medical treatments that are more conservative include hormone therapy. Gonadotropin-Releasing Hormone Agonists (GnRH) cause amenorrhea (the absence of menstrual bleeding in reproductive aged women) and decrease fibroid size rapidly. GnRH is prescribed prior to some other surgical treatments mentioned above and is not appropriate for long-term use. Oral contraceptive pills have been prescribed to control menorrhagia (prolonged or profuse blood flow) but have not consistently been proven to reduce the size of uterine fibroids. There is no evidence that this approach is effective (Stewart 2001; Center for Uterine Fibroids 2011). Fibroids may recur following all of the above-mentioned treatments, except for the hysterectomy (Evans and Brunzell 2007; Center for Uterine Fibroids 2011).

A growing number of Americans are seeking complementary and alternative medicine (CAM) options for treatment of medical conditions; in 2007, almost 40 percent of adults in the US had used CAM therapy in the past 12 months (Barnes, Bloom, and Nahin 2008; National Center for Complementary and Alternative Medicine (NCCAM) 2011). The “complementary” aspect of CAM refers to the use of CAM in conjunction with conventional medicine (hospital, surgeries, MDs etc.). The “alternative” component refers to the use of CAM in lieu of conventional medicine. CAM use by Americans is usually complementary in nature (NCCAM 2011). Three broad categories encompass CAM therapies and include: natural products (herbal medicines, minerals, natural products), the mind and body (meditation, yoga, tai chi), and manipulative body-based practices (chiropractic, massage therapy)

(NCCAM 2011). Increasing numbers of women with uterine fibroids are seeking alternative therapies to treat symptoms and improve quality of life without pharmaceuticals and surgeries (Mehl-Madrone 2002).

In 2002, Mehl-Madrone reviewed the successful histories of traditional Chinese medicine, North American herbs, acupuncture studies, and meditation studies that have ameliorated the affects and decreased the size of uterine fibroids, highlighting the importance of treating mind, body, and spirit. In a pilot study to investigate the effectiveness of a CAM treatment regime compared to conventional medicine in fibroid treatment, Mehl-Madrone found that the growth rate and size of fibroids can be affected by CAM (Mehl-Madrone 2002). Although CAM treatment costs were higher than the conventional (non surgical) comparison group, they were still lower than an uncomplicated hysterectomy, and patient satisfaction was also higher (Mehl-Madrone 2002). Liu reviewed different uses of traditional herbal medicines featuring a Chinese herbal formula (Gui Zhi Fu Ling Wan) comprised of five different herbs that were clinically confirmed to effectively decrease or eliminate fibroids (of diameters less than 5cm) (Liu 2011). Finally, regarding holistic treatments that pertain to Black women specifically, natural health practitioner, Queen Afua, who is internationally known for providing holistic wellness information and treatment options, wrote a book in 2002 titled, *Heal Thyself for Health and Longevity*. In this book, Afua dedicates a chapter to womb wellness explaining natural holistic remedies, and healthy eating (mainly vegan) regimes to reduce and/or eliminate uterine fibroids (Afua 2002).

#### *Associated Costs of Uterine Fibroids*

Quality of life costs associated with symptomatic uterine fibroids have been mentioned above, however, there are substantial financial costs that should be considered as well. In 2000, the total direct medical cost to treat uterine fibroids in the US was above \$2 billion with nearly \$1.6 billion specifically attributed to inpatient treatment services for hysterectomies (Flynn et al. 2005). These numbers have increased substantially in 10 years. Using 2010 estimates, the annual direct cost of fibroids including

surgery, hospital admissions, outpatient visits, and prescription drugs ranged from \$4.1-9.4 billion. For non-surgical management of clinically significant fibroids (hospitalization, outpatient visits, and medication), the total direct costs ranged from \$3.27-5.1 billion annually, equating to a \$5,563-8,665 cost per patient (Cardozo et al. 2012). Another study using national claims data from 1999-2004 found that women undergoing UFE incurred the highest medical costs (\$20,634) during the operative year compared to women who underwent myomectomy (\$18,674), hysterectomy (\$17,390), endometrial ablation (\$13,019), and women treated non-surgically during the year of diagnosis (\$8,257) (Carls et al. 2008). A major symptom of fibroids is heavy bleeding. Côté and colleagues found that, compared to non-heavy bleeders, heavy bleeders work 3.6 fewer weeks per year and they estimated that on average, women who experience heavy bleeding lose \$1692 per year in wages due to missed work (Côté, Jacobs, and Cumming 2002).

Uterine fibroids can cause significant decreases to quality of life due to their symptomatology, treatment management, and financial burden. Black women's disproportionate affliction with uterine fibroids is particularly concerning given the historical implications of control over Black women's fertility and past mass sterilization efforts. Physicians today are more inclined to offer hysterectomies as the preferred treatment for a condition that primarily affects Black women. The percentage of hysterectomies with a diagnosis of uterine fibroids was 68 percent among Black women compared to 33 percent among white women (Keshavarz et al. 2002). Several risk factors associated with fibroids have been grounded in studies with predominantly white women samples, and Black women have a low participation rate in clinical research trials for uterine fibroids (McCarthy-Keith et al. 2010). Emphasis should be placed on the significance of uterine fibroids and Black women's experiences.

#### SIGNIFICANCE OF UTERINE FIBROIDS AND BLACK WOMEN

In the US, fibroids have historically disproportionately affected Black women more negatively than other women (Kjerulff et al. 1996; Wise et al. 2005). Some of the earliest research took a biological

approach to explaining these differences. Witherspoon and Butler (1934) suggested that the frequent occurrence of uterine fibroids in Black women was due to sustained elevated levels of estrogen as a result of pelvic inflammatory disease (Witherspoon and Butler 1934). Earlier researchers also found a lower incidence of fibroids among the “pure African Negro” and could not attribute the higher incidence among “American Negro” women to heredity (Miller and Ludovici 1955). Perhaps the social conditions (Jim Crow Laws) in which Black women were living during the 1930s and 1950s when these studies were published (and today) increased the likelihood of fibroid tumor growth. Another earlier study of women in Maryland undergoing hysterectomy found that: the overall prevalence of fibroids was 59 percent of white women and 89 percent of Black women, the average age at diagnosis for Black women was 37.5 years and 41.6 years for whites, Black women had hysterectomies at a younger age (41.7 years) than white women (44.6 years), and Black women’s uteri weighed more and were larger than white women’s (Kjerulff et al. 1996). The authors also found that Black women were more likely to have seven or more fibroids (57 percent) compared to white women (36 percent), and Black women were more likely to have more severe and more troublesome symptoms (anemia, severe pelvic pain, constipation, stomach aches) than white women (Kjerulff et al. 1996).

Although the etiology of fibroids remains unknown, more current research specific to Black women reveals different risk factors when compared to white women. For example, one study revealed that premenopausal Black women had higher levels of ovarian hormones than white women, which have been associated with increased risk of fibroids (Woods et al. 1996; Haiman et al. 2002). Additionally, reproductive history and obesity have not explained the racial disparity for higher prevalence of fibroids among Black women, even though these were found to be risk factors in studies with predominantly white women samples (Marshall et al. 1998; Kjerulff et al. 1996). Likewise, smoking and caffeine consumption had inconclusive associations with uterine fibroids in predominantly white samples but these were not related to fibroid risk among an all Black women sample; however current

consumption of alcohol (particularly beer) was associated with an elevated risk for fibroids (Wise et. al 2004). As evidenced here, research has found that etiology and risk factors for uterine fibroids varies by race and very few scientists have targeted their research efforts on Black women exclusively outside of The Black Women's Health Study.

The Black Women's Health Study, which began in 1995, is currently the only prospective cohort study of a nationally representative sample of Black women aged 21-69 in the US (Rosenberg, Adams-Campbell, and Palmer 1995). Researchers like Wise and colleagues (2004) mentioned above and others, have used the rich data collected from The Black Women's Health Study to investigate reasons for the disparity found between Black and other women with uterine fibroids. For example, a 2007 study examined the perceptions of racial discrimination and risk of uterine fibroids among Black women and found that perceived racism was associated with an increased risk of fibroids among US born Black women (Wise et. al 2007).

Another study investigated dairy intake and risk of fibroids, and found that there was a reduced risk of fibroids associated with dairy consumption; the more dairy consumed, the less likely one is to have fibroids (Wise et al. 2010). Researchers also found a small positive association of Glycemic Index with fibroid risk and a slightly stronger association of Glycemic Load in younger women, and Glycemic Index in college educated women (Radin et al. 2010). Glycemic Index is a measure of the effects of foods on blood-sugar levels and Glycemic Load is an index indicating the amount of carbohydrate contained in a specified serving of a particular food. Lastly, Wise and colleagues found that an increased risk of uterine fibroids was associated with the use of hair relaxers (used by millions of Black women to chemically straighten their hair) among women enrolled in The Black Women's Health Study (Wise et al. 2012).

Studies like The Black Women's Health Study are especially important because, as noted earlier, many of risk factors associated with fibroids have been grounded in studies of mostly white women, yet

the condition disproportionately and more adversely affects Black women. Additionally, quantitative studies that discuss nationally representative samples of women are also important to shed light on the disparities in fibroids among women of different racial groups. Qualitative studies are equally critical and necessary because such research can also explain the thought processes, reasons for particular decisions about treatment, the impact of fibroid management, and other important factors associated with having uterine fibroids. These studies should also explore the distinct perspectives and experiences of the women who are most adversely affected – Black women.

One London-based study used a phenomenological approach and examined women's experiences with fibroids using semi-structured interviews with 18 women (Nicholls, Glover, and Pistrang 2004). Of the 18 women, most were white women (13), with one Asian woman, and four African/Afro-Caribbean women. The goal of the study was to describe women's understanding and experiences of having fibroids using the "self-regulation model" as a framework. They explored how women experience their fibroids, how they understood fibroids, and whether their experience with fibroids influenced their levels of distress. The authors identified eight themes that they clustered into two higher-order themes, "managing uncertainty" and "struggling between defeat and optimism" (see Figure 2). The women brought up issues of doctor-patient discordance in treatment options, the lack of information available about fibroids, and the effects that fibroids had on them (Nicholls et al. 2004). Of the women in the study, half of the women were found to have clinical levels of anxiety and 22 percent were clinically depressed.

Higher Order Theme: Managing Uncertainty	Higher Order Theme: Struggling Between Defeat and Optimism
<ul style="list-style-type: none"> <li>• What is normal?</li> <li>• Seeking knowledge</li> <li>• The doctor's viewpoint and the woman's viewpoint</li> <li>• It's going on and on</li> </ul>	<ul style="list-style-type: none"> <li>• Thinking about fibroids</li> <li>• Not leading the life I aim to live</li> <li>• Effects on the self and others</li> <li>• Gaining control</li> </ul>

**Figure 2. Themes and Sub-themes of Experiences with Fibroids**  
(Nicholls et al. 2004)

In another qualitative study, Askew (2009) compared the experiences of women with uterine fibroids who underwent either a hysterectomy or a myomectomy. The analysis was centered on the two treatment choices, rather than on the lived daily experiences of the participants. Askew's research yielded five themes: 1) information, 2) attitude toward body, 3) attitude toward doctors, 4) influence of family and friends, and 5) the issue of fibroids growing back. Her study revealed a discrepancy between those who had hysterectomies and those who had myomectomies in regards to the amount of information received about treatment options. In the sample, 70 percent of the women who had hysterectomies lacked an understanding about their options or their condition. Askew (2009) provides useful information about patients' experiences with doctors and the influences of family, partners, and friends on treatment decisions.

#### *Research Gaps*

Nicholls and colleagues (2004) describe several limitations to their research, which included the lack of detailed exploration of cultural and ethnic factors. They mentioned that two Afro-Caribbean women spoke about the shame of discussing illness (in general) in their communities, but their statements regarding this shame did not explicitly relate to their conceptualization of fibroids and was not included in the final list of themes. In addition, the London study hypothesized that the lack of participation among non-whites (N=5) in their study might be explained by this shame of discussing illness, indicating a need for further research in this area because women of different cultural backgrounds may have greater difficulty in reaching consensus with their doctors (Nicholls et al. 2004). Using a Black feminist approach in their study might have produced a more fruitful analysis of the unique experiences Afro-Caribbean women have with uterine fibroids.

In Askew's (2009) analysis of treatment decisions, the sample was predominantly white (78 percent white (N=14), 22 percent Black (N=4)) and did not lend ample attention to the unique experiences of Black women participants. Furthermore, Askew (2009) underscored the importance of



further investigating the theme, “attitudes toward doctors” regarding women’s experiences with fibroids. These issues could be explored further by considering that Black women’s attitudes toward doctors may be shaped by both racial and gendered factors.

While limited, the studies mentioned in this section have contributed greatly to research on fibroids in the medical field, public health, and psychology. Yet much remains uninvestigated. Given racial disparities in healthcare, we know little about how race and gender may inform Black women’s social and personal experiences with fibroids as well as how they manage medical care. In the few qualitative studies of women with fibroids, none of them exclusively address Black women’s experiences while taking into consideration the racial and gendered dynamics of this medical condition. How Black women cope with such stereotypes, reproductive injustices, and lack of autonomy as patients in the medical arena, in addition to the impact of intersecting oppressions (being Black, female, and having a medical condition [uterine fibroids]), warrants a deeper analysis.

## THEORETICAL FRAMEWORK

### *Illness and Health-Seeking Behavior*

*Sick role.* In 1951, Talcott Parsons became a major contributor to sociology for his structural-functionalist analysis of society, by providing one of the first major theoretical concepts in medical sociology, the “sick role.” Parsons explained that people fall into the sick-role when they experience illness, which he defined as, “a state of disturbance in the ‘normal’ functioning of the total human individual” (Parsons 1951: 430). A person who is sick then enters this socially sanctioned deviant role because their normal functioning is inhibited by their illness, but it is only sanctioned if it is policed by the medical profession. While helpful in understanding the role of the medical profession, the “sick role” has limitations in that it does not address chronic illnesses, when people are blamed for their illnesses (for example obesity and its consequences), when either the patient or physician rejects the illness, and it does not address differences in the doctor-patient relationship (intersections of race, class, and

gender are not addressed) (Rier 2010). In relating the “sick role” to women who suffer from symptoms associated with uterine fibroids, one must ask if they are assigned a “sick role” and if so, whether they accept it with all of its conditions. Will non-compliance with unwanted treatment options (for example someone refusing a hysterectomy) alter the ability to be “legitimated” in the “sick role”?

*Illness behavior.* Eliot Friedson (1970a) further investigated illness behavior with his research on patient roles. Friedson approached illness from a symbolic interactionist lens where he developed three types of legitimacy in regards to state of illness which complemented Parsons’ (1951) “sick role.” These types are “conditional legitimacy”, “unconditional legitimacy”, and the “illegitimate deviant.” In conditional legitimacy, deviants (sick people) are temporarily exempt from normal obligations and gain extra privileges, *if* they seek help to get better. In unconditional legitimacy, deviants are exempt permanently from normal obligations and gain privileges because they cannot help their illness. An illegitimate deviant is someone who is exempt from normal obligations because of their illness, which they may not be responsible for but are subjected to stigma and gain few if any privileges. As these types of legitimacy have not been well tested or verified, his insights illustrate how illness is a socially created label and offers a way to describe different sick roles (Friedson 1970a; Cockerham 2004). For Black women with uterine fibroids, their legitimacy may be determined by them (depending on whether or not they consider themselves in the sick role), their peers, employers, or physicians. Research on patient’s roles provides an additional analytical frame in which to view Black women’s experiences with fibroids.

*Illness experience.* After one has decided, or someone has decided for them, that they are sick or ill, understanding the illness experience itself presents another analytical framework. Psychiatrist Arthur Kleinman (1988), distinguished between disease and illness, where disease is a physiological condition that is treated by a physician objectively and illness is the lived experience of patients and their social networks (Rier 2010). In his book, *Illness Narratives*, Kleinman (1988) argues that illness narratives

inform researchers and practitioners about how problems are created, controlled, and made meaningful. “They [illness narratives] also tell us about the way cultural values and social relations shape how we perceive and monitor our bodies, label and categorize bodily symptoms, interpret complaints in the particular context of our life situation; we express our distress through bodily idioms that are both peculiar to distinctive cultural worlds and constrained by our shared human condition” (Kleinman, 1988: xiii). Sociologists Anselm Strauss and Barney Glaser in the 1970’s, and later Kathy Charmaz in the 1990’s researched the chronic illness experience through ethnography and in-depth interviews (Glaser and Strauss 1965; Strauss and Glaser 1975; Charmaz 1991; Rier 2010).

Some aspects of work by Kleinman (1988), Strauss and Glaser (1965, 1975), and Charmaz (1991) on illness narratives of chronically ill patients are applicable to this study of uterine fibroids depending on how the women classify their condition. An important aspect of this study incorporates the narratives of illness or disease. Does it matter if women classify uterine fibroids as an illness, disease, or something else entirely? Incorporating a qualitative approach that elicits narratives allows for a more productive assessment of wellness and illness narratives, and understanding Black women’s interactions with, or avoidance of, the Western medical system and medical professionals.

*Health seeking-behaviors.* Edward Suchman’s (1965) research sheds light on doctor-patient interactions. He found that one’s cultural background and healthcare utilization was characterized by belonging to one of two groups of people, cosmopolitan and parochial. He found that people belonging to cosmopolitan groups demonstrated low ethnic exclusivity, had fewer friendship systems, and were not close to family. They were more likely than the parochial group to trust health professionals and were more knowledgeable about disease. People belonging to parochial groups have close relationships with family, friends, and people of their ethnic group. They were more likely than cosmopolitan group members to delay seeking healthcare. People in parochial groups referred to close networks to cope with illness or seek recommendations for a course of action and were less knowledgeable about disease

(Suchman 1965). The research on doctor-patient interactions and patient roles may inform research on how and if Black women interact with the healthcare system regarding their fibroids. Given that Black women have varying levels of education, class, and medical knowledge, it is informative to analyze their health-seeking behavior considering Suchman's framework.

### *The Medical Profession and Medical Knowledge*

The sociological examination of the medical profession also provides great insight into how to analyze Black women's experiences with gynecologists regarding uterine fibroids. Eliot Freidson (1970b), Paul Starr (1982), and Peter Conrad (2007) examined how the profession of medicine monopolized power and authority in health, hospitals, and medical schools to advance their own interests, also highlighting the important role of the domineering American Medical Association. In the past, medical professionals were the only "gatekeepers" of healthcare and had great power (professional dominance) over patients and their treatment options (Starr 1982). Today, however, people have access to medical knowledge via the Internet and social networks, are able to challenge medical professionals with regard to diagnoses and treatment.

In line with professional dominance, Conrad proposed medicalization of conditions or illnesses as a source of control over what is deemed a medical problem. Conrad defines medicalization as a problem "defined in medical terms, described using medical language, understood through the adoption of a medical framework, or "treated" with a medical intervention" (Conrad 2007:5). Research on medicalization has centered around the medicalization of non-pathological occurrences like menstruation and childbirth, as opposed to more pathological conditions like terminal illnesses. It is useful to bear in mind this concept of medicalization in regards to Black women and fibroids. While fibroids are in a sense medicalized, they need not always be treated with medical intervention. Analyzing the implications of "medicalizing" fibroids and medical dominance over Black women's treatment can offer new perspectives in medical sociology. Recall that a hysterectomy is considered to

be the only “cure” for uterine fibroids and involves the complete submission of one’s body to a surgeon. In this study of Black women, the theoretical framework of professional dominance is particularly useful because how the women choose to treat their fibroids is relative to the doctor-patient interaction.

### *Women’s Experiences*

Researchers have also made significant contributions regarding medical sociology research and women’s experiences. In a study of women who had elective hysterectomies, Lorentzen (2008) examined women’s experiences of doctor-patient interactions and the nature of medical power. While she did not characterize the racial/ethnic composition of her sample, the women varied in age (30-67), education, and income (\$10,000-\$250,000). Lorentzen (2008) found that some physicians used particular medical power techniques specifically because the patients were female. The women in the study only resisted medical power after they assessed the accuracy of the physicians’ claims, and used a variety of “knowledges” (lay medical, knowledge about power regimes, and experiential knowledge) to resist medical power techniques. Forms of resistance included indirect and sometimes passive challenges to physicians’ truth claims, such as ending relationships with non-compliant physicians without informing them. Physician compliance is essentially the physicians’ willingness to comply with the patients’ desired course of treatment for a medical condition. Women also sought compliant physicians until satisfied, or avoided medical care all together (Lorentzen 2008). Black women with uterine fibroids who are actively seeking treatment, or interacting with gynecologists or physicians, contribute a unique set of “knowledges” to resist medical power techniques that is dependent upon the type of physician compliance they experience.

Seear (2009), an Australian sociologist, applied the concept of “menstrual etiquette” to the study of endometriosis (a menstrual condition with similar symptoms to fibroids). Menstrual etiquette is the act of women concealing their menstruation to avoid stigma. This concept has direct relevance to this study of uterine fibroids among Black women. Seear (2009) found that women’s experiences and

discussions with doctors and others about their painful or abnormal menstruation violates menstrual etiquette, stigmatizing women who suffer from endometriosis, and creating a normalization of pain associated with menstruation and confusion in the ability to determine normal versus abnormal periods. The study examined how women experiencing menstrual problems perceived their vulnerability to social sanctions for their condition, how they strategized to avoid stigmatization, and the role of others in facilitating and encouraging concealment of menstruation (Seear 2009). The implications for this research are that, counter to previous studies, women are able to distinguish between “normal” and “abnormal” menstruation, but to avoid stigma and social sanctions they minimize the pain and fail to disclose menstrual problems (Seear 2009). The strategies identified by Seear are informative to this study of Black women suffering from uterine fibroids, as one interdisciplinary study of Black women affirmed a there was an avoidance of, or negative discussion, surrounding menstrual events (Cooper and Koch 2007).

#### *Medical Sociology and Black Feminist Epistemology*

While there have been no sociological studies that explicitly examine uterine fibroids among Black women using a Black feminist approach, researchers have used a Black feminist framework to study other health issues and can offer guidance for the present study. Mary Abrums’s (2004) analyzed how Black women use religious beliefs to cope with and resist racist, discriminatory objectification that they experience in healthcare (healthcare in a general sense). While using the four dimensions of Black feminist epistemology outlined by Collins (2000), Abrums (2004) collected information through interviews, casual conversations, and sermons or biblical narratives by women. Her study revealed that Black women resisted objectification and resistance in healthcare through complaints, direct challenges to providers, refusal to go to the doctor, prayer, and other subtle forms (Abrums 2004). The application of a Black Feminist framework allowed a more nuanced discussion about the role of religion in coping with illness and Black women’s experiences of interacting with the healthcare system.

Quinn Gentry (2005) used a Black Feminist perspective to examine how various living conditions impacted HIV risk-behavior among low-income Black women. Gentry's analysis illustrated how low-income Black women at risk for HIV "have unique 'within' group needs that must be addressed for effective prevention intervention" (Gentry 2005:248). She emphasized the need to legitimate the wide range of experiences within groups of Black women to better understand their risk factors and identify interventions that were empowering while considering the structural barriers to HIV prevention and Black women's agency (Gentry 2005). The 2011 American Public Health Association (APHA) Annual Meeting featured a workshop with Quinn Gentry titled, *Advancing Black Feminist Theory and Practice in Public Health*, emphasizing the need for more health research using this epistemology (APHA 2011).

#### *Application*

Black women's particular experiences with conventional medicine may impact how they experience fibroids. However, there is a paucity of research that deals with the qualitative experiences of Black women and health, especially research on fibroids. The proposed study seeks to fuse Black Feminist thought with medical sociology by including Black women in the sociological framing of illness and wellness narratives. Given the history of racial mistrust between doctors and patients, how are Black women framing their condition? How do Black women conceptualize having fibroids? The history of the exploitation of Black women's bodies by the medical profession and society, may affect how women in this study experience and manage uterine fibroids, and how they interact with physicians today. Empirical research about how Black women manage and experience uterine fibroids is needed.

#### RESEARCH QUESTIONS

The overarching question this study will address is: "How do Black women frame the condition of having uterine fibroids?" Thus, I to investigate a) how Black women conceptualize having fibroids, b) whether Black women's conceptualizations of fibroids affect feelings about selves or their lifestyles, c) the mechanisms, if any, by which Black women deal with uterine fibroids, d) whether or how their

multiple race, class, and gender identities affect their illness experiences and the types of treatment, if any, that they seek, and e) how conventional and complementary/alternative medicine shapes Black women's experiences with fibroids.



## CHAPTER 3: METHODOLOGY

### RESEARCH DESIGN

As this study is not just about women's experiences, but Black women's experiences, it was essential to employ not only feminist research methods, but use dimensions of Black feminist epistemology with regards to recruitment, data collection. The dimensions of a Black feminist epistemology embody: the collection of concrete experiences as a criterion of meaning, the use of dialogue to assess knowledge (connecting rather than separating), ensuring an ethic of caring, and being accountable for knowledge claims that are made (Collins 2000). While several authors have provided great insight around conducting research with a Black Feminist framework or through an intersectional lens, there is no step-by-step guide or concrete methodology for conducting research through a Black feminist lens (Mullings 2000; Few, Stephens, and Rouse-Arnett 2003; Choo and Ferree 2010).

Choo and Ferree (2010) advise that while giving voice to the participants, the researcher should not write for the readers who are unfamiliar with their experiences, but write for their participants. While this study is about an issue that directly affects me, being a Black woman with fibroids, it has been and will continue to be about and for the women in this study. There were several instances before I finalized my dissertation topic, where members of the target population encouraged me to conduct this study, and the research participants throughout the process continuously endorsed the study as well. So I wrote this dissertation for them, and will be accountable for the knowledge claims they have made by writing *for them* and being reflexive in the process.

Incorporating a Black Feminist epistemology into this analysis requires transparency and iterations of reflexivity throughout the methods, results, and conclusions of this dissertation. "Reflexivity takes several forms: (1) Full explanation of how analytic and practical issues were handled; (2) Examination of the researcher's own background and its influences on the research; and (3) Reflections on the researcher's own emotions, worries, feelings" (Olsen 2007:423; Neill 2006). Additionally,

methodological discussions about how to conduct research using a Black Feminist epistemology are lacking and this dissertation seeks to fill that void.

## RECRUITMENT

To ensure diversity a variety of locations and strategies were used for recruitment, ranging from medical to holistic institutions that specifically service low-income women to agencies that service wealthier women. Initial recruitment for the study began April 17, 2012 through word-of-mouth. In an effort to attract the target population, I created a recruitment flyer that incorporated images of Black women and the uterus (see appendix A). I sent the flyer to friends, family, coworkers, and peers to circulate the flyer on my behalf. Some friends and family posted the flyer on their Facebook pages and sent emails to other people in their networks. Response was immediate, and participants were scheduled for interviews the following week. After the initial word-of-mouth phase, 10 interviews were scheduled over the course of 2 weeks. Thereafter, the recruitment efforts were spaced out to avoid having more participants contact me than I could schedule.

The second phase of recruiting involved me posting the flyer on my personal Facebook page for friends and family to share with potential participants, and on public Facebook pages about uterine fibroids and other networks of people that would forward the information (five Facebook pages). Another 10 participants were recruited via the second phase, for an N of 20. Meanwhile, through snowball sampling, participants who had been interviewed were asked to share information about the study to those they thought would be interested; five additional participants (N=25) were scheduled (Weiss 1994).

For the final phase of recruiting, a friend posted an advertisement on Craigslist with my flyer (1 participant was recruited through Craigslist) and I began posting paper flyers in various locations throughout Atlanta and on email list-serves of which I am a member. I requested permission and posted flyers at: The Feminist Women's Health Center (Facebook and on location), Sister Love, Sister Song,

Grady Memorial Hospital, and The Center for Black Women's Wellness (Facebook). A work colleague at the Centers for Disease Control and Prevention who is also an OB/GYN offered to recruit participants at the clinic where she worked. The combination of the three recruitment phases allowed me to recruit and interview 31 participants from April 14 – July 2, 2012. Theoretical saturation had been reached, as no new information was revealed during the last few interviews (Strauss and Corbin 1998; LaRossa 2005; Draucker 2007).

#### SAMPLE

Participants included in this study were between the ages of 27 and 62 and had been medically diagnosed with uterine fibroids. The sample included Black women who self-identified as Black, African-American, American, bi-racial, Caribbean, Jamaican-American, and Nigerian. Due to the nature of fibroids, participants varied in their experiences with fibroids including women who: do or did not suffer symptomatically from their fibroids, suffer from symptoms in varying degrees, are currently in the process of deciding how or if to treat their fibroids, have already chosen and undergone treatment for their fibroids, and those who have opted for no treatment at all. Household income for participants ranged from \$24,000 to \$300,000 and education ranged from high school diplomas to PhD. Several women were currently enrolled in school working on either a BA/BS, MA/MS/MPH, or PhD. Table 1 includes detailed demographic information about the participants in the study.

Table 1. Participant Demographic Information

Participant	Race/Ethnicity	Sexual Identity*	Household income	Children	Education	Age	Marital Status*	Treatment***
Josephine	Mixture/ American	H	\$33,000	0-Desired	HS, some college	61	S	Hysterectomy
Alfre	American	H	\$200,000	4 (2 biological)	MA	54	M	Hysterectomy
Elise	American	H	\$300,000	2	JD	43	M	UFE, myomectomy
Robin	American	H	\$81,000	0-Desires	BA	27	M	Wait and see, CAM
Dihann	African-American	H	\$200,000	3	PhD	58	M	Wait and see/menopause
Zoe	Black-American	N	90-95000	0-Will adopt	MPH	35	S	Myomectomy, laparoscopic myomectomy, UFE, pending partial hysterectomy
Jill	Caribbean	H	\$90,000	0	MA, PhD^	31	M	Wait and see, CAM
Eartha	African-American or Black	H	50-75,000	0-Desires	MPH	37	M	Wait and see, CAM
Taraji	Black and other	Q	110-115,000	0-Desires	BA, MA^	36	M	Hysteroscopic myomectomy, myomectomy, CAM
Della	Black, Guyanese born	H	\$60,000	3	MA	54	M	Wait and see/menopause
Jasmine	African-American	H	\$90,000	0	BS	37	S	Wait and see
Dorothy	African-American	H	\$80,000	0-Trying now	JD, MS	40	M	Hysteroscopic myomectomy x 2
Ruby	African-American	H	75-80,000	0	BA, some MA	52	D/S	UFE, partial hysterectomy, CAM
Chandra	African-American	H	\$50,000	0	MA, MSW^	46	S	Myomectomy
Pam	African-American	H	\$80,000	3	HS, some college	52	M	Wait and see, CAM
Lynn	Jamaican-American	H	175-180,000	2	MSN	43	M	Myomectomy, D&C, UFE, CAM
Beverly	African-American	H	\$11,000	0-Desires	AA	62	D/S	Myomectomy, D&C x 2, ablation, CAM
Patience	African-American	H	75-80,000	1	MA, ThD^	45	D/S	Myomectomy, hysterectomy, CAM
Sophie	African-American	G	\$200,000	1	JD	40	P	Laparoscopic myomectomy
Whitney	Caribbean	G	\$100,000	1	BA	35	P	Laparoscopic partial hysterectomy, CAM
Lena	Biracial (White/ Black)	H	\$50,000	0-Desires	MS, MBA	36	P	Hysteroscopic myomectomy
Nell	Black	H	\$200,000	1	MSN	47	M	Wait and see/Menopause
Phylicia	Black	H	\$90,000	1	HS, BA^	49	M	UFE, menopause, CAM
Debbi	African-American	H	\$24,000	1	AA, BSN^	49	D/S	UFE, hysterectomy
Wendy	African-American	H	\$57,000	0-Desired	MSW	39	S	Hysterectomy
Loretta	African-American	H	\$90,000	5 (2 biological)	AASN	55	D/R	UFE, hysterectomy
Cicely	African-American	H	\$100,000	1	BS	60	D/S	Laser procedure, hysterectomy
Halle	African-American	H	\$100,000	0-Desires	HS, Technical School	41	M	Hysteroscopic myomectomy, myomectomy, CAM
Lisa	African-American	H	\$98,000	1	MPH, MA	36	E	Myomectomy
Leleti	Nigerian, Black	H	\$78,000	3	DVM, MSC, PhD, MPH^	45	M	Wait and see, CAM
Nia	African-American	H	\$61,000	0-Desires	MA, PhD^	36	S	Wait and see, CAM

\*H=Heterosexual, N=No labels, Q=Queer, G=Gay

\*\*S=Single, M=Married, D=Divorced, P=Partnered, R=Re-married, E=Engaged

\*\*\*UFE=Uterine Fibroid Embolization, CAM=Complementary and/or Alternative Medicine, D&amp;C=Dilation and Curettage, Menopause=waiting for menopause

^Program in progress

## DATA COLLECTION

Between April 14 and July 2, 2012, I conducted 31 in-depth, face-to-face interviews. Participants interested in the study either called or emailed me to set up an interview. As participants contacted me, they were screened for inclusion by being asked if they had been medically diagnosed with fibroids and if they were Black or of African descent before an interview was scheduled. All of the participants who contacted me met the inclusion criteria, however three women living in other states contacted me wanting to participate. They were thanked for their interest, but were not included in this study for logistical reasons. Based on several discussions with Black women who have uterine fibroids, I knew that the topic was salient and many women wanted to discuss their experiences. Therefore, an incentive for participation was not necessary. As a Black woman with uterine fibroids, I also capitalized on our shared racial, gender, and “medical” identity to gain access, establish rapport, and ensure the collection of rich data. Participants chose the location of the interviews; most of which took place in their homes (N=14) or in an office at their places of employment (N=11). With feminist methodologies in mind, the interview format was semi-structured to allow the participant to guide a majority of the interview; however, I also drew from a series of topics and questions that I wanted to explore (Reinharz 1992).

In Collins’ (1989) Black feminist epistemology, it is important to ensure an ethic of caring throughout the research process that acknowledges that participants are unique, emotions are transparent, and empathy is expressed. Initially I was not sure whether or not – or when – to share my personal experiences with fibroids, so I let the interview dictate my disclosure. In the first six interviews, I disclosed some of my experiences because the participant knew me to have fibroids and asked about my treatment decision, or they were curious about my desire to study this topic. One participant, Jill, advised me to be more open about my experiences at the beginning of the interview so that people would feel more connected to me and the research process. I then created a script that I began using at the beginning of each interview:

Thank you so much for agreeing to participate in this study. First, I think it's important that I explain why this study is so important to me. I myself was diagnosed with uterine fibroids in 2007 and have had an interesting journey myself with my own symptoms, concerns, and with doctors. My interactions with the healthcare system are what sparked my investigation into other Black women's experiences. The questions I have are about your experiences with uterine fibroids. Some questions are broader than others so that you can interject ideas that I have not considered. Please feel free to introduce issues that are relevant to your particular experience. Our interview will be tape-recorded and I will take notes during our conversation. Do you have any questions before we get started?

Another important feature of using a Black feminist epistemology is to use dialogue to assess knowledge (connectedness rather than separation) (Collins 1989; 2000). At the beginning of the interview I also said, "I want this to feel more like a dialogue than a list of questions that need to be answered." By creating a space for open dialogue between myself and the participant, I was able to reduce social distance, make the participant feel at ease by developing a good rapport, which I believe enhanced the research experience as Reinharz (1992) suggests.

Other feminist approaches I employed throughout the research process involved active listening and engaging participants in the research process (Weiss 1994; DeVault 1999). I was a compassionate and active listener, who was sensitive to differences among participants. I also promoted dialogue by asking several follow-up questions that led to very rich data. Participants were included in the research process by being asked to review their transcripts for accuracy (four women completed this task). At the end of the interview, participants were given the option of creating their own pseudonym to be used in the study results, however some of them were not suitable. Some women wanted to use their real names because they wanted to be transparent, one woman wanted to use Scooby Doo, and another Milk Chocolate. Ultimately, the first names of famous Black female actresses were used as pseudonyms for this study to maintain anonymity. While I wanted participants to feel more involved in the research process, I learned there were better ways to do this. For example, I asked participants, "What did you think of the interview? Is there anything you would change or like to see added?" Respondents indicated that the active listening and inclusive process were beneficial to their participation, and disclosure of information.

*Demographics Survey and Interview Guide*

After the disclosure statement mentioned above, most interviews began with me informing the women that I was going to ask them some questions about their background to get a sense of “who they are, where they’re from, and where they’re going,” followed by the collection of fairly standard demographic questions. After the demographic questions, I incorporated a quiz to get a general idea about the woman’s knowledge of uterine fibroids. The quiz questions came from a previous study about fibroid treatment decisions (Solberg et al. 2009) and were adapted for this study with an additional question about Black women and uterine fibroids. Following the demographic survey and quiz, I began the semi-structured interview portion by asking the participant to tell me about her experiences with uterine fibroids since they were diagnosed or became symptomatic. Depending on the conversation, I then asked follow-up questions related to their response and directed the interview by asking questions in the interview guide (see Appendix B for full interview guide and demographic survey).

In line with a feminist approach I shared resources and information that I had come across in my research and personal experiences with fibroids whenever it was relevant, or if a participant specifically asked about something. Alternatively, some women offered me resources to try and recommended medication that I had not tried or heard about. This reciprocal sharing of information between interviewer and participant exemplifies Black Feminist epistemology through ensuring an ethic of caring through transparency and empathy. Additionally, some women expressed apprehension and concern about a particular treatment they were considering or getting ready to undergo, and I was able to share some valuable information from previous interviews that was helpful for them. Collins (2009) posits that Black feminist practice represents a dialogical relationship characterized by Black women’s collective experiences and group knowledge. “Knowledge for knowledge’s sake is not enough – Black feminist thought must both be tied to Black women’s lived experiences and aim to better those experiences in some fashion” (Collins 2009: 35). While this was part of the intent of this research, it was fulfilling to be

able to help other women *during* the research process, and not just at the end when the dissertation was complete.

Prior to study recruitment, Institutional Review Board approval was obtained from Georgia State University and an informed consent form was signed and collected from all participants at the beginning of each interview. The duration of the interviews ranged from 55 minutes to one that was 2 hours and 45 minutes, which had to be broken into two different days. Each participant was interviewed only once and the interviews were audio-recorded using a Livescribe smart pen with a special lined-journal. This allowed me to take notes in such a way that did not distance me from the conversation because I was able to capture every word seamlessly. The Livescribe smart pen not only records the audio portion of the interview, but also the hand-written notes in the special lined-journal with built-in dot patterns. According to Lincoln and Guba (1985) recording devices can be intrusive, and can fail at times; being able to use the pen as both a recording device and writing utensil was discreet and ensured hand-written notes in the event of technical failure. Upon docking the pen and syncing it to the computer, all notes are uploaded into an Adobe PDF file along with its associated audio recording. All data (audio recordings, notes, and transcripts) were stored on a password-protected computer, in a password-protected folder to ensure and maintain participant confidentiality.

#### DATA ANALYSIS

A modified version of Grounded Theory Method (GTM) was used to analyze the interviews and present emerging themes and participant generated theories. GTM is a set of procedures used to generate theory from empirical data, and the extensive coding process helped me identify intersections between race, class, gender, and having a medical condition such as fibroids (Glaser and Strauss 1967). The three primary coding phases used in GTM include *open coding*, *axial coding*, and *selective coding* (Strauss, 1987). The original descriptions of how to employ these coding procedures can be confusing and difficult to follow; therefore the condensed methods proposed by LaRossa (2005) were used for this analysis.



With GTM, coding typically begins soon after data collection begins, to ensure adequacy of the sample and to allow the researcher to know when theoretical saturation has been reached. My modification of GTM began here, as I did not begin an official coding process until after the data were collected and transcribed. I did keep a journal during data collection that helped me determine when theoretical saturation was reached. In the journal, I wrote any analytical thoughts I had about the interview, what changes – if any – should be made in the interview guide, and any recurring themes I noticed from prior interviews. I also wrote about activities associated with recruitment, the environment in which the interview was conducted, my thoughts and feelings that day, colleagues I may have talked to about the process, articles I was reading, and any other thoughts that might have come to mind during the data collection period. While I did not transcribe and code the interviews throughout data collection, I feel this process was a suitable substitute and also allowed me to determine when no new information was emerging from the interviews.

### *Using Dedoose*

Qualitative research has progressed in the sense that you can code qualitative data electronically as opposed to manually underlining, writing in the margins, literally cutting up quotes from transcripts, etc. I chose to analyze my data using Dedoose, a relatively new web-based software that was created by researchers at UCLA ([www.dedoose.com](http://www.dedoose.com)). The company offers a free one-month trial, after which membership is only \$12.95 per month. The software is unique in that it allows for the analysis of both qualitative and quantitative data on one platform. Dedoose is web-based, meaning there are no downloads, or licensing agreements to deal with, and it is very intuitive and easy to use. I found the tutorial videos, coding capacity, and visual analytical tools very useful in filtering the data and allowing core variables to emerge.

In Dedoose, the media you intend to analyze can be word documents, videos, or audio files. I uploaded the interview transcripts (individual Microsoft Word documents) titled by the participant's ID

number. Dedoose allows the researcher to link the participant's demographic information to their transcript or media file as a descriptor. To link the demographic information/descriptors, I created a Microsoft Excel file that included participant demographic information such as their age, racial identity, their treatment decision, whether or not they had health insurance, etc. I uploaded the descriptor Excel file, and another Excel file (data definitions file) that included information about the variables in that file. Each media file (participant transcript) had to be individually linked to the descriptor data. Uploading the files and linking the media to the descriptors took about 20 minutes.

This analysis of Black women's experiences with uterine fibroids will contribute greatly to the production of Black feminist thought around Black women and health. The use of GTM through a Black feminist lens allowed these women (through my interpretive lens) to make substantive knowledge claims about their unique experiences with uterine fibroids.

Black feminist thought's potential significance goes far beyond demonstrating that Black women can produce independent, specialized knowledge. Such thought can encourage collective identity by offering Black women a different view of themselves and their world than that offered by the established social order. This different view encourages African-American women to value their own subjective knowledge base. By taking elements and themes of Black women's culture and traditions and infusing them with new meaning, Black feminist thought rearticulates a consciousness that already exists. More important, this rearticulated consciousness gives African-American women another tool of resistance to all forms of their subordination. (Collins 1989:750)

Analyzing the data from a Black feminist perspective provides an added layer by allowing me to also look for intersections of race, class, gender, and health throughout the coding process. The following sections outline the three phases of coding and the process by which I analyzed the data through an intersectional lens.

### *Open-Coding*

The first phase of coding, open coding, involves breaking down the data into parts and analyzing the text line by line. In this stage of coding, concepts and variables are created from indicators (words, phrases) within the text being analyzed. Concepts are the labels or names associated with the indicators

in the text (LaRossa 2005). Initially, I read through six printed transcripts line by line. During this process I underlined words and phrases that were interesting to me, wrote comments and questions in the margins, and I kept a memo. Words that were thought to be potential variables or concepts were also written in the margins next to their respective indicators. After I completed this process for each interview, I logged into Dedoose to enter the codes and link the indicators. I found this process to be counter-productive, because it included a lot of backtracking and slowed the analysis process tremendously. After I finished entering the codes for the initial six printed transcripts into Dedoose, I continued the coding process only using Dedoose. The reason I did not do this initially was because you cannot enter notes in the margin, or underline text in Dedoose. You can however, write memos that are linked to each participant's file and create excerpts that can be linked to codes, concepts, and memos that you create. Using Dedoose, I read through the remaining transcripts line by line, excerpted quotes that were indicators for previously identified codes/concepts or created new ones, and wrote memos for each participant that I coded.

I used Glaser's (1965) constant comparative method to compare new indicators to previously coded indicators as concepts were formed. As new codes emerged in subsequent interviews, I reviewed previously coded interviews for indicators of newly developed codes. I kept track of these steps in an analysis journal. Most of the initial concepts that I created were based on the questions being asked of the participants. For example, the concept "discovery," was related to the participants' response when asked how they found out they had fibroids. An indicator for this concept was, "Well before I got diagnosed, I felt something . . . I mean I could feel this lump, this ball you know. So I didn't know what that was, so I finally asked them what it was and that's when they told me it was fibroids." In order for a variable to develop, there needed to be dimensionality within the concept. The "discovery" concept had added dimension because I could add categories for women who had discovered their fibroids on their own, their doctor had discovered their fibroids, or something else contributed to their discovery. The

concept had dimension because there were three types of discovery, and therefore became a variable. If there was no dimension then the concept remained a concept. While some concepts may not have developed into variables, some were very prominent and important throughout the analysis despite their lack of dimension.

The constant comparative method also posits that, “while coding an indicator for a concept, one compares that indicator with previous indicators that have been coded in the same way” (LaRossa 2005:841). Throughout the open coding process I constantly compared previous excerpts of codes to newer excerpts to validate the meaning of the code. For example, several participants described a lack of understanding in their doctor-patient relationship. I created a variable called doctor-patient relationship with several dimensions based on the type of doctor-patient relationship the women expressed: lack of understanding, trust/comfort, caring, conversations, partnership, positive, and negative. The lack of understanding dynamic in the doctor-patient relationship was exemplified by six different interview excerpts, of which two are shared below:

Excerpt 1: I don’t know his exact words... but the bottom line was like, it’s all messed up in there, you just need to take it out. Like basically, this is like... I’m only 30, so I don’t have any kids, and you’re basically telling me it’s a wrap, you might as well just go on and take it out, with no empathy, no anything. I was like, dude! (laugh) I just came out of anesthesia, you’re telling me this. So I was a little emotional about that, I don’t remember crying in front of him, but I remember like crying and being all upset, not so much about the not having kids, but just the way in which he said it. Like I was pissed off! (Wendy)

Excerpt 2: I guess people don’t understand, when you don’t have kids and it’s something that you want, and I always thought that I would be a mom. So I don’t think she understands how, the only reason I had not agreed to a hysterectomy or something of that sort is because I’m trying to hold on, and I don’t think people get it. They just don’t get it. (Jasmine)

#### *Open-Coding through a Black Feminist Lens*

Analyzing through a Black Feminist lens was constantly at the forefront of my mind during the open coding process. Early on in this phase, I created a code called “intersectionality” to capture indicators that talked about either intersecting identities (Black woman, older Black woman, Black

female nurse, or Black female with multiple health conditions). This allowed me to view the data through an intersectional lens. When women talked about feminism, the text would often be coded as a representation of intersectionality. Essentially women discussed feminism as something for white women; one person even said it was for white gay women. An excerpt would get coded as intersectionality if it brought up any of Collins' "controlling images" of Black women or brought to mind the unique plight of Black women's experiences (Collins 2000). I also would code an excerpt as intersectional if the participant mentioned race and gender when referring to their doctor, without my prompt. This let me know it that it was something significant for the participant. Lastly, intersectional could also mean that a participant has other medical conditions that intersect with their experiences with fibroids. I thought those were important to capture, like women who have or have had cancer in other parts of their bodies, endometriosis, or other issues.

At the end of the open coding process I had created 50 core concepts/codes most of which had 2-10 sub-codes, for a total of 237 codes. The list of codes was extensive, and some had representation of excerpts from a majority of participants while some only had excerpts from 1-2 participants. Additionally, some codes had anywhere from 1-280 excerpts associated with a particular concept. Below, Table 1 lists all of the concepts/codes created during the open coding process. The first column lists the concepts that were created, and the second column includes all sub-codes, or the dimensions associated within a particular concept. For example, with the concept, "care-seeking behaviors", I wanted to capture what type of healthcare seeking behavior the participant utilized in general. Some women described not going to the doctor unless they absolutely had to, or if all of their initial self-treat methods were not working. Some concepts did not have sub-codes either because I had not yet decided how to create dimension for a particular concept or I just wanted to capture excerpts at a more general level. For additional details on my open coding process, see Appendix C for examples of the variable-concept-indicator models for "patient agency" and "treatment decision."

Table 2. Concepts Created During Open-coding Process.

Concept/Code	Sub-codes
Abnormal normal	
Birth Control	
Embarrassment	
Bodies	(medicine, self)
Care-seeking behaviors	(CAM, does not like dr., does not like medicine, goes to dr. (proactively or reactively), relative/friend is doctor/nurse or they are, self-treat/research initially)
Class	
Control	(over decisions, over fibroids)
Decision	("wait and see", avoiding/researching/self treat (CAM), during/after Rx experiences, feelings about Rx decision, impact of Rx decision, process, satisfaction with decision)
Discovery	(dr. found, she found, feelings about, other (what prompted to go to dr.))
Dr. Preference	(bedside manner, convenience, expertise, gender, honesty, listens/understanding, none, other, race, recommendations)
Dr. Recommendation	(birth control, hysterectomy, myomectomy, other, pain killers/medication, patient research based on dr. recommendations, UFE, "wait and see")
Dr./Patient Relationship	(caring, conversations, feelings about, negative, trust/comfort, lack of understanding, partnership, positive)
Effects of Research	(why participated)
Etiquette	
Expectations	
Family History of Fibroids	
Feminism	(Is she?, how?, what is it?)
Fibroid Definition/Description	
Fibroid Knowledge	(fairly knowledgeable, little knowledge, very knowledgeable)
Fibroid conversations	
Fruit	
Great Quotes	
Gynecological Experiences	(dr. conversations about fibroid symptoms before diagnosis, goes regularly, out of gynecological care)
Healthcare system/insurance and fibroids	(how much for fibroid treatment?, socialization of healthcare)
Illness/Disease	(definitions, "it's not cancer")
Impact	(ability to have children, embarrassment, fatigue, heavy bleeding, intimacy, lifestyle, other, pain, thoughts, unable to associate impact on life, bladder, feelings about, financial, low iron, work)
Intersectionality	(other)
Letting go	
Medical fears	(clinical trials)
Menstrual History	(cramping, heavy period)
Motherhood vs. Treatment options/Importance of motherhood	(impact on birth)
Network of Fibroid sufferers	(coworkers, family, friends)
Other	
Patient Distrust of doctors	(intersectionality)
Patient agency	(management of care, research, recommendations for other women)
Perceptions of Doctors' Intentions	(all about the money, feeling's about, neglect, positive)
Religion	
Reproductive History	(conversations about reproductive health, cycle (heavy bleeding, cramps), pregnancy)
Research Questions	(affect of conceptualization on self and lifestyle, CAM experiences with fibroids, conceptualizations of fibroids, coping with fibroids, intersecting identities and illness/Rx experiences)
Self-Blame	(for fibroids, for hysterectomy, for infertility, for other, for unsatisfactory Rx decision)
Social Capital	

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Sojourner Syndrome or "Keep it Moving"	("keep it moving" from dr., from mom or family member, thoughts or feelings about)
Something positive	
Support	(family, intimate partner, media, other, support for Rx decision, from network of fibroid sufferers, social)
Symptoms	(body enlarged/changed, discomfort, fear of symptoms, frequent urination, heavy bleeding, nausea, other, pain, return of symptoms after Rx, unexpected bleeding, anemia, clotting, constipation, sexual/intimacy/discomfort)
Wanting more options	(avoiding hysterectomy)
What causes fibroids in general?	(birth control pills, multiple theories, other (lack of children/no child yet), diet, estrogen, genetic, stress, structural/environmental, unknown, weight gain/lack of exercise)
Why Black women?	(because we're Black?, diet, disparities in access to certain items, feelings about, genetics, not sure, other, stress of being Black, exposure to certain things, lifestyle, should be researched/screened more, stress in general)
Womanhood	

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### *Axial Coding*

Axial coding refers to the intense analysis around one variable at a time where questions and hypotheses are developed. In essence, researchers during this phase move beyond descriptions and are trying to create relationships between or among variables to how they are influenced by each other (LaRossa 2005). For example creating a relationship between a participant's agency as a patient and her intersecting race, class, and gender identities. A type of question that I asked during this process was, "what type of women have a strong patient agency, and how does that impact their relationships with their physicians, or their treatment decisions?" Another question was, "what variables influence the impact of uterine fibroids on these women's lives?"

As axial coding requires intense analysis around one variable at a time, doing this for about 50 variables/concepts would be too cumbersome and unnecessary because it was very evident that some variables were more theoretically saturated than others. Some concepts and variables had hundreds of indicators representing a single concept or variable. The variables identified for axial coding were selected through a two-staged process. First, using Dedoose, I determined which codes had the most indicators, or representations in the data. Naturally, a respondent may have multiple indicators for one code. The second process involved using Dedoose to identify the codes that were well represented in the data based on how many respondents were represented for that code. For example, every

participant (31) was coded at least once for “fibroid conversations”, and the code had 86 indicators in the data. In the end, 11 variables were axial coded: conceptualizations of fibroids, coping with fibroids, doctor/patient relationship, fibroid conversations, impact of fibroids on life, “keep it moving”, motherhood vs. treatment options, patient agency, support for fibroids, symptoms of fibroids, and treatment decisions.

During axial coding I posed questions centered around the 6C’s (causes, contexts, contingencies, consequences, covariances, and conditions) outlined by LaRossa (2005). For each variable that I axial coded, I asked the following questions in considering the 6C’s: 1) what are the conditions that give rise to this phenomenon? What causes this phenomenon?; 2) what is the context in which this phenomenon is embedded?; 3) what are some of the intervening conditions that mediate this phenomenon?; 4) what are the action/interaction strategies and tactics in which this phenomenon is handled, managed, or carried out?; 5) what are the consequences of these strategies, or what does this phenomenon cause or influence?; and 6) what are the co-varying variables associated with this phenomenon, if any? Initially, it was difficult to answer the questions, so to initiate this answering process I asked myself the “who, when, why, how, and what consequences” for each variable which served as a primer for the 6C’s. The final step in axial coding was to consider the memos that I may have written during open coding about a particular variable. Details of my axial coding process for 11 variables are presented in Appendix C.

#### *Axial Coding through a Black Feminist Lens*

As I coded From a Black feminist perspective during axial coding, I was constantly thinking about how being a Black female, and embodying other intersecting identities, might mediate some of their experiences for each focal variable. When doing axial coding with the variable, “patient agency,” I felt that an important intervening condition that would mediate one’s patient agency was intersecting identities. For example, the negative controlling images of Black women in the media, discussed by Collins (2000), coupled with contradictory messages from parents, peers, and social institution have



impacted how Black women discuss sexuality and what is shared with doctors (Rouse-Arnett and Dilworth 2006). This history of secrecy and shame certainly would mediate or influence a Black woman's patient agency. Additionally, one study found that open communication with their mothers influenced Black women's gynecological visits by them feeling more prepared as opposed to those who had limited communication with their mothers about gynecological health (Warren-Jeanpiere, Miller, and Warren 2010). Depending on how a respondent was socialized she may have a strong patient agency or weak patient agency, which is important to think about when considering intervening variables for patient agency. Another example of axial coding with a Black feminist lens is demonstrated by how Black women conceptualize fibroids. Because many Black women in this study associate fibroids with Black women, it definitely impacts their beliefs about how and why fibroids develop, particularly for them as Black women.

### *Selective Coding*

The final coding phase, selective coding, entails the identification of a core variable that is theoretically saturated and centrally relevant. The core variable is the one that occurs frequently, and is most often and easily related to other variables (Strauss 1987). A core variable, 1) must be central and related to as many other variables as possible, 2) must appear frequently in the data (indicators too), 3) must relate easily to other variables, 4) have clear implications for a more general theory, 5) the theory moves forward appreciably, 6) the variable allows for maximum variation (Strauss and Corbin 1998).

To choose the core variable, I again used a multi-staged process. First, because the core variable should be related to as many other variables as possible, I determined which three variables from axial coding related to the most variables. Respectively, those variables were "treatment decision," "doctor-patient relationship," and "patient agency." I then used Dedoose to identify how many indicators were associated with each variable because the core variable must also appear frequently in the data as indicated above. Treatment decision had 251 indicators, doctor-patient relationship had 96, and patient

agency had 83 indicators. Next, I outlined storylines for each of the three variables to depict how variables interacted with each other and influenced the core variable, as well as what resulted because of the core variable. Details of the selective coding process are outlined in Appendix C.

### *Selective Coding through a Black Feminist Lens*

While selective coding with a Black feminist lens, I incorporated an intersectional framework into the stories I crafted. For example, for the variable “doctor/patient relationship,” the unique history that Black women have had with the medical field has an impact on this relationship. Likewise, if a Black woman also has other health challenges to deal with (breast cancer, thyroid cancer), the way she interacts with doctors might be different because of her prior experiences and interactions with medical professionals compared to someone who has fibroids and it is her first major health challenge. In another scenario, some women in this study are nurses, and this additional identity also alters the their doctor patient relationship as they negotiate whether to share their nurse identity with their doctor. During this process, I made it a point to always consider how intersectionality fit into the overall stories that were being developed for each core variable.

### ROLE OF RESEARCHER

I would be remiss if I did not discuss the implications of my role as researcher, and how this may have impacted the research process. Being that I am a Black woman who was diagnosed with uterine fibroids at age 28, I was able to connect to the women on several levels. Through my own experiences and additional background research conducted for this dissertation, I was extremely knowledgeable about uterine fibroids, the common terminology, and treatment options associated with fibroids. As an added element, I was also familiar with symptoms, some coping strategies, and the impact that fibroids have on quality of life. Therefore, the research questions were influenced by my insider status, and experiences. This could have impacted the process negatively in that my questions could have been self-serving and not indicative of what respondents deemed important. However, I feel that my insider

status had a positive effect on the interviews with regard to building rapport with participants, expressing genuine empathy, and knowing which questions to ask next. An outsider may have yielded good information, but I feel that being an insider allowed women to be more open and candid with their responses and share more information.

Though my experiences as a Black woman with fibroids enhanced the study and likely lead to richer data, I still contended with the fact that I was a researcher. I was careful not to appear as the expert, because I wanted them to embrace themselves as experts on their experiences and conceptualizations of uterine fibroids. It truly was a dialogue in that participants often asked me what I had tried for my symptoms, or what treatments I was considering, and I openly shared with them as they did with me. Moreover, some participants were working on their PhD's and could relate to the research process in general. Several women chose to participate not just because it was a topic of great concern that should be researched, but also because they wanted to support me as Black female researcher examining something that greatly impacted their lives. I felt like their little sister in that regard, and I had only just met most of these women when they contacted me for an interview.

#### LIMITATIONS OF THE STUDY

This study is not without some limitations. Blacks and other racial/ethnic minority groups are often treated as a homogenous group in health research; likewise interventions and policies have been implemented as such. However, Blacks, similar to other racial/ethnic groups are a heterogeneous group of varying socioeconomic status, geographical origins/locations, education, and religion (Williams & Jackson 2000; Earl & Penney 2001; Braun 2002). While my sample was fairly diverse, unfortunately I was unable to capture the amount of diversity I sought. Four of the 31 participants were born outside of the United States, while household income ranged from \$24,000 to \$200,000, most of the sample was above \$50,000 and they were a fairly highly educated group of women. While some women spoke of experiences when they had less money, or were less educated, I would have preferred to have more

class variation, ethnic diversity, and representation from different geographic locations. Additionally, the age range of participants was 27-62, but more than half of the participants were 40 years of age or older with an average age of 45. Because of the implications that fibroids have on reproductive processes, it would be important to hear more about the stories of women in their 20's and 30's who are making treatment decisions for fibroids, especially those who desire but have yet to have kids.

Methodologically, other options could have been explored. With regard to temporality of data collection, while I was able to assess some of the women's experiences over time, because fibroids often recur after treatment, it would have been opportune to follow the participants over time to see how their experiences changed. I have continued to speak with the women in my study following their interviews. Following up with the participants was more a reflection of my inherent personality and caring nature, but I also think it is inherent in using a Black feminist epistemology. Continued interaction with participants has allowed me to develop friendships, check on their well-being, and get updates on their treatment decisions; however a longitudinal design was not built into the methodological framework for this study.

## OVERVIEW OF DISSERTATION

In speaking with Black women about their experiences with uterine fibroids, conversations were largely focused on their decisions for treatment. While "treatment decision" was identified as the core variable during the selective coding process, there were other important narratives to be considered in conjunction with the treatment decision. Medical sociology literature explores how disease and illness is constructed and experienced, in addition to the treatment decision-making process. Throughout interviewing and during analysis, four interrelated elements related to Black women's experiences with fibroids emerged: conceptualizations about fibroids, experiencing fibroids, treating fibroids, and patient agency. How one conceptualizes fibroids influences how she experiences them, the treatment decisions that she chooses, and how that decision is also moderated by the doctor-patient interaction and patient

agency. The remaining chapters will incorporate how Black women's intersecting identities impacted their experiences with uterine fibroids.

Chapter Four, Conceptualizing Uterine Fibroids, will begin by describing how Black women socially construct the meaning of fibroids and their theories about fibroid etiology. The social construction of fibroids is relevant to how women experience symptoms, therefore, Chapter Five, Experiencing Uterine Fibroids, will illustrate these experiences, how they deal with the impact of fibroids on their life, and the strategies for coping with symptoms. Conceptualizations about fibroids are linked to the treatment decisions that are made. Chapter Six, Treatment Decisions, will examine the treatment decisions that were made, the decision-making process, and how their lives were impacted by their decisions. Chapter Seven, Patient Agency and Black Feminism, will examine Black feminist activism from the standpoint of Black women with uterine fibroids. Specifically it will discuss the role of patient agency within the doctor-patient interaction, and how Black women's unique social positions influence these factors. Lastly, chapter eight concludes with an overall summary of findings, discussion, implications, and directions for future research.

## CHAPTER 4: CONCEPTUALIZING UTERINE FIBROIDS

### INTRODUCTION

The social construction of illness emphasizes how the meaning and experience of illness is shaped by cultural and social systems (Conrad and Barker 2010). In essence, our ideas about illness are not biologically determined, but are shaped by socialization, conceptualizations, and structural influences. According to Brown (1995):

We may consider the social construction of a phenomenon to involve a multiplicity of social forces that combine to create and modify the phenomenon. Rather than a given biomedical fact, we have a set of understandings, relationships, and actions that are shaped by diverse kinds of knowledge, experience, and power relations, and that are constantly in flux. (P. 37)

Additionally, other proponents of this perspective add that a social constructionist perspective for illness means, “. . . metaphors of illness are theory and value laden . . . there is no absolute truth about etiology . . .” (Petersen, Heesacker, and Schwartz 2001:216). Examining how a patient constructs illness is important and sociologically relevant because, “The illness, what the patient is doing about it, and how it is experienced is a product of the patient’s constructions, and these constructions have been derived in large part from the sociocultural context” (Petersen et al. 2001: 216). Therefore understanding how Black women define fibroids and understand their etiology is an essential foundation from which to begin the discussion about Black women’s experiences with fibroids. This chapter will explore how Black women construct the meaning of fibroids for their lives, and how their ideas about the etiology of fibroids are rooted in their race-gendered histories, lifestyle, and their social location in society.

### WHAT ARE FIBROIDS?

In the biomedical literature, uterine fibroids are simply described as uterine leiomyoma, uterine fibroids, benign tumors in the uterus, etc. They are not consistently labeled as an illness, disease, or condition. With similar ambiguity, the International Classification of Diseases Version 10 (ICD-10), “a

standard diagnostic tool for epidemiology, health management, and clinical purposes”, describes leiomyoma of the uterus as “benign neoplasms of the uterus” with sub-codes for submucosal, intramural, subserosal, and unspecified (WHO 1992; WHO 2013). Timmermans and Haas (2008) argue that social scientists studying health and illness have largely focused on the social aspects of health-related topics (sociology of diagnosis, medical authority, etc.), and tend to ignore what matters most to patients and health care providers who deal with specific diseases in everyday life. What has remained under-explored is the dialectical relationship between social life and disease, as medical sociologists are apprehensive about the role of biological and genetic factors, thus devaluing the social factors. One way to focus on what is relevant to patients and health care providers is to start sociological investigations at the diagnosis of disease or illness as opposed to how it became an illness, or if it is real or socially constructed. In reality, for these women fibroids represent a concrete biological phenomenon, that yields both biological and social consequences, and they are less concerned with whether or not they are factual, or who discovered them. This section will briefly highlight how women conceptualize having fibroids and what it means. Prominent throughout their definitions of fibroids are value-laden descriptions that are rooted in their intimacy with the condition and how it impacts their lives.

Respondents were recruited based on their having been medically diagnosed with fibroids, and this was used as a starting point for this study. To assess the meaning of fibroids for women in this study, respondents were first asked to describe fibroids in their own words and whether or not they considered the condition to be an illness or a disease. As doctors and medical researchers have defined fibroids as “benign tumors in the uterus,” so did a substantial number of the women in this study (N=14). Literally, they defined them in single statements, “a growth in the uterus, like in various size balls,” non-cancerous tumors in the uterus,” “abnormal growths,” “a muscular growth,” “misguided estrogen,” and various descriptions of growths associated with the uterus.

However, nearly half of the respondents (N=15) also defined fibroids with terms that were indicative of their symptomatic experiences with fibroids, and the emotional and functional impact on their life. Women defined fibroids in terms of their symptoms with phrases like, “I would describe them as painful,” “painful problem,” “Hmmm, the first thing that came to my mind was painful,” and “pains in the ass, literally.” When asked to describe fibroids in their own words, responses were sometimes a reflection of what was important to them, which was most often the pain that fibroids caused. Far from simply just benign tumors, for these women, emotionally the tumors represented, “Misery and pain,” they were “aggravating,” “horrible!,” “embarrassing,” “bothersome,” a “nightmare,” and one called them “demons.” Their definitions of fibroids are constructed based on what fibroids meant for them and their lives, and how they have made the women feel. Lastly, definitions of fibroids were constructed in relation to the functional impact on their life and body. Respondents explained that fibroids were, “a malfunction,” “very inconvenient,” “it totally disrupts your life,” and fibroids are “not something that’s life threatening, but it’s definitely a nuisance.” As evidenced through their own definitions of fibroids, their meaning represents more than that of a “benign tumor in the uterus.” For several women what it means to have fibroids is rooted in their experiences with symptoms, the emotions that they evoke, and their general impact on life.

Respondents were also asked whether they classified fibroids as an illness or disease to determine whether or not it was related to their conceptualizations about fibroids. Women were most likely to classify fibroids as neither an illness nor a disease (N=16), and often described it as a condition, an ailment, a nuisance, an abnormality, or a challenge. These discussions with women who classified them as neither reflected a resistance to acknowledging that something was wrong or being placed in a “sick-role.” The recurring theme throughout their de-classification process was that fibroids are not as serious as other diseases and illnesses like cancer, and should not be relegated to that status, despite the severe symptoms and impact on their lives.



## WHY DO WE GET FIBROIDS?

As explained in Chapter two, the true etiology of fibroids remains unknown. Previous epidemiological and medical studies have found that fibroid growth is stimulated by increases in estrogen in the body (Miller and Ludovici 1955). Also, recall that researchers found a decreased risk of fibroids for women who had children, used oral contraceptives, weighed less, and smoked cigarettes (probably due to decreased appetite and weight loss) (Ross et al. 1986). These studies did not ask the women (mostly white) who were experiencing the fibroids about their thoughts on the etiology of fibroids. While more recent studies have used quantitative methods to examine the social, structural, and cultural factors associated with fibroid growth (major life events, sexual and physical abuse during childhood), they too have not tapped the source of their inquiries for their perspective on the etiology of fibroids (Vines et al. 2010; Boynton-Jarrett et al. 2011; Wise, Palmer, and Rosenberg 2013). Black women's ideas about fibroid etiology are sociologically relevant because they reflect their understanding of fibroids and influence their decisions about treatment.

For women in this study, conceptualizations about fibroids are not only rooted in their personal experiences with them as illustrated in the previous section, but also the cultural and social contexts in which the women live. Recall that Petersen and colleagues (2001) stated that from a social construction of illness perspective, "there is no absolute truth about etiology" (Petersen et al. 2001). Whether it comes from gynecologists, research scientists, or epidemiologists, there is no one truth about the etiology of fibroids. Moreover, Shim's (2005, 2010) research on the conceptual divide between lay people of color living with cardiovascular disease (CVD) and the epidemiologists who study CVD is relevant here. The expert knowledge among epidemiologists is taken-for-granted because of the "relative absence of an arena in which lay and scientific causal claims come into explicit interaction and contestation" (2005:430). She also argued that epidemiologists "might have much to gain from the diverse knowledge constructed by lay people with CVD" as it relates to the understanding of race, class,

and gender effects on cardiovascular health (Shim 2005: 234). The present study takes into consideration the concrete experiences of women who are most impacted by fibroids and illuminates the importance of cultural, structural, and social influences on understanding fibroid etiology.

Collins (2000) posits that Black women have a unique standpoint from which they experience a variety of everyday life events, and that these experiences can be accessed, analyzed, and rearticulated through Black feminist thought as critical social theory (Collins 1986). One distinguishing feature of Black feminist thought, “concerns the essential contributions of African-American women intellectuals” that represent Black women from all class levels, occupations, both inside and outside of academia (Collins 2000:33). Essentially, all Black women are capable of producing theories about the commonplace, taken-for-granted knowledge that is gained in everyday thoughts and actions, which represent Black feminist thought. Black women who experience fibroids on a daily basis have unique thoughts about the etiology of fibroids that differ from prior quantitative and biological studies and Black feminist thought is an appropriate tool through which to initiate a lay-science dialogue about fibroid etiology.

In general, the women discussed a variety of causes for fibroids which included: genetics, diet, stress, estrogen, null-parity (not having given birth), structural and environmental factors, weight gain, unknown reasons, and a combination of several reasons. When specifically asked about Black women’s disproportionate affliction, respondents shared ideas related to race, gender, and class as additional explanations for the more severe symptoms and increased diagnoses among Black women. It is important to note that most women believed there were multiple factors at play and that the true etiology of fibroids could not be attributed to a solitary source. Lynn and Jill clearly articulate the complexity.

Lynn is a nurse with a lot of background on women’s health issues, particularly related to cancer. Lynn expressed in several instances throughout the interview that fibroids could not be attributed to just one thing. She shared, “it’s genetic as well because my grandmother had it, my mother

has it, my sister just got diagnosed with it.” However, in her opinion Black women are impacted more by fibroids because of “genetics, BMI, increased adipose tissue, estrogen production, and androgens, and our diets.” She elaborated on the importance of diet, with respect to foods high in estrogen, but she cannot attribute fibroids to just one thing. Lynn’s educational and occupational background, coupled with her lived experiences with fibroids all contribute to her conceptualizations about fibroid etiology coming from multiple sources.

Jill offered a detailed account of her three-pronged theory about the etiology of fibroids. Jill explained that fibroid etiology was rooted in a, “physical, emotional, and structural” manner. As she discussed her reasoning, she drew from her own personal experiences with fibroids and her beliefs about the lives of Black women in general. Physical reasons for fibroids were attributed to diet and her reading about the impact of certain foods on fibroids. Emotionally, fibroids were related to stress, and that Black women “in particular are under an undue amount of stress.” Structurally, she associated fibroids with Black women having to deal with racism and limited access to certain amenities. However, after being asked about the increased likelihood of Black women to have fibroids, she responded from a more global perspective as well:

I think the medical industry kind of trivializes Black women’s problems. They may not pay much attention to it, or downplay it in a sense. Also, this kind of culture of secrecy, [where] you’re not supposed to talk about anything related to your reproductive functions. Also, the stress and strains of being a Black woman in the modern world; and I say modern world because in Jamaica, women have fibroids at an astronomical rate too. . . . You always hear it [fibroids] in the discussion of American, U.S. Black women, but you know there are women around the world, Black women around the world that experience it too. You kind of wonder wow, what’s the variable here that can control for all of the locations? What’s going on? So I think the stress and strains of the modern existence, and also the access to healthcare. Because disproportionately, Black women have either perceived or experienced barriers to equitable healthcare. So awareness is one thing.

Her intricate conceptualizations about fibroid etiology are a reflection of her educational background and her Caribbean identity. There is diversity among Black people across the African diaspora, but according to Jill Black women across the world share a common burden that contributes to their

disparate rates of fibroids. Jill explained how the trivialization of Black women's problems by the medical industry has grave implications for how Black women deal with and discuss gynecological issues. Her thoughts about fibroid etiology illuminate the complexity of the condition. There are interlocking reasons for increased rates of fibroids among Black women that include individual, structural, and cultural factors.

Some women further described contributing factors that were indicative of their race, class, and gendered identities. Three prominent themes emerged: race-gendered histories involving heredity and genetics, unique stressors related to being Black and female, and the ways that poor diets lead to Black women being disproportionately overweight. The themes described in the following section have been parsed out of their full context to clearly articulate their main ideas.

#### *Genetics and Race-Gendered Histories*

Given that epidemiological research has been unable to pinpoint the true etiology of uterine fibroids as discussed previously, naturally scientists, geneticists, and biologists have also explored the potential role of genetics. For example fibroid diagnosis was twice as likely for women who had two or more immediate family members with fibroids, and the predisposition of Black women to fibroids indicates a genetic component may be involved as well (Kjerulff et al. 1993; Vikhlyaeva, Khodzhaeva, and Fantschenko 1995; Marshall et al. 1998; Ligon and Morton 2000). These studies suggest a genetic component associated in the etiology of fibroids, which warrants further genetic studies and has implications for gynecologists to inquire about family histories (Ligon and Morton 2000; Stewart and Morton 2006). In fact, two current studies are underway to look at the role of genetics and fibroid etiology. The Center for Uterine Fibroids at Brigham and Women's Hospital is investigating siblings in their, "Finding Genes for Fibroid Study," and one component of an NIH prospective study out of Detroit called, "Study of Environment, Lifestyle, and Fibroids (SELF)" is looking at the role of African ancestry in risk for uterine fibroids among 1600 Black women (Center for Uterine Fibroids 2013; SELF 2013). It is not

surprising then that, according to several women in this study (N=11), one of the most common reasons they gave for why women develop fibroids, is genetics.

Ironically, during our conversation, Beverly mentioned her participation in the above-mentioned Brigham study, “Now I participated in a study, but it wasn’t a clinical trial. I think I provided my email, with Brigham University in Massachusetts.” Her participation in this study correlates to her belief about why women get fibroids. Beverly felt that fibroids were a result of “misguided estrogen,” but when asked if there were any other reasons why she felt she had fibroids, she said it is “Heredity, I think. I’m one of five girls, and all of us have fibroids. But my mother didn’t.” She went on to explain why she felt it was related to her father’s side of the family as opposed to her mother’s:

I think its genetics. I think, my father had two sisters, and although I don’t know why they didn’t have children, all the brothers had children, of course, but his two sisters never had children. Neither of them, and I suspect it might have been fibroids. We talked about that, and we associated that our mother didn’t have fibroids and she had six children, neither my father [because he is a man], so we traced it back to my father’s sisters. We could be wrong, but I don’t think so.

Beverly’s theory about the etiology of fibroids being genetic was directly related to her known familial history of fibroids, which she had traced and determined through investigation. Fibroids are passed on through genes that she attributes to her fathers side of the family. While studies have examined the genetic component of fibroids, none have been able to confirm the connection. Beverly affirmed this as her reality through her assessment of her family history. Several women spoke of tracing their family history and finding that other women had fibroids. However, the women added another layer to the genetics argument by incorporating the race-gendered histories of Black women.

Loretta also spoke also of her mother, sisters, and cousins that had fibroids and added her belief that she developed fibroids because of her race and hereditary background, “I think more so because I’m Black and because it’s in my family.” She also alluded to the fact that different groups of people are just predisposed to different ailments, “It’s a culture thing I guess. Everybody has there I guess their designated things that they will go through, it’s just our lot. Maybe we can handle pain better or

something, I don't know" [laugh]. Here with Loretta, we start to see the implications of fibroids being common among Black families and how race/ethnicity is tied to these experiences. Statements such as, "it's just our lot," normalize fibroids among Black women specifically identifying a race-gendered etiology for fibroids.

Much along the same lines as Loretta, Nell also discussed the predisposition of the Black race to certain diseases:

It's irritating. It makes me angry. 'Cause we have everything. We have the most breast cancer, we have the most HIV, we have the most anal cancer . . . we have the most, we have everything. We have high blood pressure, cardiac disease. Everything that we have, we have more of it. I don't know maybe we have more stress in our lives.

Nell is referring to the disparate rates of heart disease, diabetes, HIV, breast cancer that she has seen in her line of work as a nurse, among Black people in the United States. Her thoughts about Black people having the worst health outcomes inform her conceptualizations that she has fibroids because she is a Black woman, and a history of diseases that disproportionately plague Black communities. When asked whether or not she classified fibroids as a disease or illness, she rationalized, "No. I classify it as being Black. If a white person tells me they got it I'm like, dumfounded. I'm like, you got fibroids? Your ass is Black" [laughing]. For Nell, having fibroids is so inextricably linked to race that she conceptualizes them as a condition for Black women only. Her ideas about Black women and their predisposition to having fibroids are rooted in her knowledge of health disparities among Black Americans for several diseases and illnesses, which has implications for unearthing an etiology that is not biologically based.

Cicely described a race-gendered fibroid etiology, "hereditary lifestyle," that was socially and structurally centered. While she also felt that she had fibroids because her mother and sister had them, she expanded on the impact of Black ancestral lifestyles:

I think a lot about African American people. I really think it's handed down. I think that [it's] because of . . . how we ate, not us, but our ancestors. I really think that that has a lot to do with it: things that they were deprived of, things that they should've had, and kind of the way we ate. Because even today, I wonder why certain things I crave, and I'm not a bad eater, but certain things I just feel as if I have to have, and I think it's from

how our ancestors lived and how they ate and what they ate. That stuff is handed down over the generations. I really think so.

While Cicely's thoughts about why Black women are more affected than white women intersects both hereditary conditions and diet, it is important to note that her conceptualization of heredity encompasses more than genetics or biology. She attributes her development of fibroids not only to the fact that her mother had them, but also to the "hereditary lifestyle" behaviors that were also passed down through generations.

Relatedly, Lena touched on "hereditary lifestyles" in the sense that familial conversations about health were missing, and Black people did not go to the doctor. For Lena, this "hereditary lifestyle" intersects with a lack of definitive diagnostic confirmation from family members, and her knowledge of fibroid symptoms:

I think that they're hereditary. I think because, especially because African-American people . . . we didn't go to the doctor. . . . My 88-year old aunt never had children, and my grandmother talks about, [it was] because she was a heavy bleeder, but what does that mean? You're talking about the twenties and thirties; you know what I'm saying? And then I had an aunt who said they put her in a mental institution because she couldn't handle her periods. What does that mean? So you know, because we didn't know our history. Is this something that we could have prevented?

Lena is essentially saying that fibroids are hereditary because she believed her aunt and great aunt had them. However, she is alluding to the fact that these women in her family were not diagnosed with fibroids, but for her the symptoms were clearly fibroid related. And whether or not they were medically diagnosed or not, the family history of these menstrual issues was not being passed down so that people in younger generations, like her, could be aware and knowledgeable. Additionally, Lena attributes this lack of information passing to be common in Black families like hers.

Cooper and Koch (2007) found that Black women tend to avoid or have negative discussions surrounding menstrual events. Additionally, intergenerational gynecological health care communication between Black mothers and daughters has been enveloped with secrecy and shame as a result of controlling images in the media about Black women's hyper sexuality (Warren-Jeanpiere 2006; Rouse-

Arnett and Dilworth 2006; Collins 2000). According to some women in this study, this socio-cultural and historical tradition impacts how Black women understand and construct reasons for their disparate rates of fibroids and knowledge of generational fibroid histories.

### *Diet and Weight*

Some women in the study had strong opinions about the relationship between diet and exercise, and fibroids. Specifically, they believed a diet that is high in fat and hormones increased one's likelihood of having fibroids, especially if one was overweight or obese. Thirteen women in this study felt that weight, diet, and lack of exercise were linked to fibroid etiology. Wise and colleagues (2005) found a complex association of fibroid growth with increased BMI, and roughly 4 out of 5 Black women in the United States are overweight or obese, and have the highest rates of obesity compared to all other groups (NCHS 2012).

Several women in this study understood the link between weight and diet and re-enforced this as a contributing factor to fibroid etiology for themselves and Black women in general. They mentioned that Black women generally have bad diets, eat too much chicken with added hormones, and consume too many soy products. A couple of women explained how their diet specifically impacted their fibroids. For example, Jill found that from her personal experiences and reading about causes of fibroids, "when I eat certain food, I feel kind of heavier in my abdomen where it is located. I think that diet, like fatty foods, most definitely plays a role in terms of the growth." The changes she observed in her body based on what she ate, influenced her ideas about fibroid etiology and how food influences their growth.

In addition to the multiple narratives about the effect of diet on fibroids, a couple of women expanded upon why Black women's diets are different from other women. Taraji explained that Black women live in environments that dictate the type of food available to them, which impacts their diet leaving them predisposed to having fibroids at a disproportionate rate:

I think possibly in some cases it is the food that we get because brown women are more likely to have them [fibroids] than white women. Often times brown women are more



likely to be victims of poverty, to be victims of under wealth, and have less access to good foods. Their markets might be full of hormone beef rather than organic foods. They'll get week-old vegetables rather than the fresh vegetables. So yes, I think it has to do with the food that we've been consuming.

She explains how race, class, and gender intersect and impact what Black women eat. She believes that consuming organic meats that include fewer hormones like estrogen, which is known to increase fibroid growth, would decrease Black women's diagnosis and affliction with fibroids. Although Taraji described diet as a reason for developing fibroids among poorer Black women, she always had a fairly healthy and organic food lifestyle.

Phylicia offered an explanation for why Black women are more likely to have fibroids and offers an example of how class impacts what Black people have been able to consume:

It could be our diet. So many Black families, Black people, they're not making a whole lot of good money. So, they're not able to go shop at Whole Foods. They're not able to buy organic. They may not live in homes with back yards where they could plant their own greens, their own veggies. So they're going to Piggly Wiggly, Wayfield Foods, where they sell junk. Pig slime, and then they're filling their bodies and their children's bodies with that junk. But, I mean, the majority of Blacks, they grow up on chitlins and fatback and pig ears and pig feet and pig tail; all the wrong things. So those that are able to buy healthy food, the majority of them are not Black. There is the disparity. So it really comes down to class. You have more whites that can afford to go to Whole Foods and buy natural chicken. Chicken fed with grain, not a bunch of mess. They're eating healthier. And our race is not. And so because of what we're ingesting, it might impact us even more.

Phylicia's narrative appears to conflate class and race; Black people generally have less money and are not able to afford healthier foods. For Phylcia, this context in which poor diet happens in Black families helps to explain the disparity in rates of fibroids for Black women. Wealth does influence the foods that one can buy, however even wealthier women can eat poorly as some women in this study disclosed. By juxtaposing Black women's knowledge claims about fibroid etiology with epidemiological studies linking BMI and fibroids, we are able to gain insight into why Black women might be overweight. More importantly, however, we see that not all Black women who have fibroids are overweight or have poor diets as evidenced by several women in this study.

### *Unique Stressors for Black Women*

Respondents explained how Black women's everyday lived experiences encompassed an underestimated, emotional, and spiritual toll that can increase one's likelihood of having fibroids and severe symptoms. These discussions came up when they were asked if they felt they had fibroids because they were Black women, and in their response to a general question about where they felt fibroids came from. Taraji best expressed this theme when sharing her beliefs about why Black women are 2-3 times more likely to have fibroids: "Girl, 'cause life is fucking rough (laugh). Shit is hard in these streets . . . you know sisters go through a lot. Sisters, we deal with a lot."

Taraji felt that the reason her fibroids initially developed, and kept developing, was because of her emotional and spiritual state of being:

I would say emotionally I think that fibroids are a manifestation of all your frustration, your pain, your depression, your denial, your aggravation, and lots of [the] time, shame. Spiritually, kind of the same – just a physical manifestation of all your stuff not being right. When I say you, I mean, me, my stuff not being right. Um, where do they come from? They come from just those places where sadness that is never expressed resides, where frustration that is never addressed resides, where shame starts, and hurt feelings. I mean I know it really sounds crazy, and stress.

The shame Taraji speaks of is that which a lot of Black girls experience in childhood, being sexually violated by a close family member or friend of the family. According to the U.S. Department of Health and Human Services, in 2010, rates of child maltreatment (physical abuse, sexual abuse, emotional abuse, and neglect) were higher among girls 9.7 per 1,000 children) than boys (8.7 per 1,000), and highest among children who were Black (14.6 per 1,000) compared to American Indian/Alaska Native (11 per 1,000), Pacific Islander (10.9 per 1,000), Hispanics (8.8 per 1,000), non-Hispanic Whites (7.8 per 1,000), and Asians (1.9 per 1,000) (HHS 2011). These are *reported* cases. Black women have a tendency to underreport child sexual abuse, and the shame and guilt related to their abuse leads to concealment (Briere and Elliott 2003; Yoshioka et al. 2003; Bowens 2007; Brazelton 2011; Singh, Garnett, and Williams 2012). Taraji shared her experience growing up and the impact that her mother's boyfriend had

on her childhood and as an adult. She believes the “places where sadness that is never expressed resides, where frustration that is never addressed resides, where shame starts” are manifestations of her painful childhood as fibroids in adulthood. From her perspective, the negative energy and stressors that Black women experience in a lifetime are often bottled up and this has implications for their health. Moreover, new research using data from the Black Women’s Health Study reported that the incidence of developing fibroids was higher among women who reported child abuse, and sexual child abuse in particular (Wise et al. 2013). This suggests that Taraji’s analysis has some support among the research community, and her contribution through this study provides much-needed context on the topic.

Patience, who is working on her doctorate in Theology, also spoke of fibroids in a similar way that is based on the unique stressors that Black women face every day. She described fibroids as a compilation of energy “that comes from our stress, our cultural societal messages . . . that solidifies in these tumor forms from all of the energy that we receive from our environment in all these different capacities . . . it’s sort of a social, spiritual, psycho thing.” Patience also helped clarify some of the unique stressors that Black women face as she eloquently explained why she felt she had fibroids,

Mine is pretty commensurate with many, many Black women in general . . . we are nurturers, we are caretakers; and then, being a clergy person . . . you got the call to do it even on another level. But we are in general nurturers and caretakers, so we are open to people, we pay more attention to them than ourselves, we allow them to impose their stress. We neglect the care that we need to have for ourselves. Consequently, these are the conditions these fibroids are in. So, I do say that there was a time that I was working entirely too hard for other people. I had a partner in my life that was just very needy and just stress came from this guy, I tell you. So, I think him, and the job, and family, wasn’t so much ‘cause it was just me and my son, but I was a single parent raising him. So just, all of the heaviness of that; when you don’t take time for yourself to evaluate and assess what it is doing to your body, then I think you give open access to these types of things happening. So yeah, I think that’s what happened to me.

Patience’s beliefs about fibroid etiology are a reflection of her pastoral work and her lived experiences as a clergy person, nurturer, and mother. Everett, Hall and Hamilton-Mason’s (2010) study among Black women identified daily stressors associated with time commitments in balancing work and family responsibilities, role strain, and financial stress. The most demanding stressors identified were people or

things that were emotionally demanding, as opposed to demanding of their chronological time (Everett, Hall, Hamilton-Mason 2010). Collins (2000) discussed how Black women's unpaid work can be both confining and empowering, but how it can also be exploited within Black family networks, boyfriends, and relatives is rather under-explored in scholarly work. Patience understands the consequences of such burdens and how they might have influenced the growth of her fibroids.

Respondents' beliefs that social conditions contribute to fibroid etiology, parallels the "weathering hypothesis" developed by Geronimus (1992). The weathering hypothesis explains such impact on illness and disease specifically as it relates to Black women:

The health status of [Black] women may begin to deteriorate in detectable ways in young adulthood as a response to perpetual social and environmental insult or prolonged active coping with stressful circumstances. Such insult may have negative implications for women's health or health behaviors. (Geronimus 1996:590)

While the weathering hypothesis has not been objectively and directly tested on Black women as it relates to fibroids, it appears that some Black women in this study attribute their acquisition of fibroids to effects from weathering as stated by Patience and Taraji. When asked if she felt she had fibroids because she was a Black woman, Pam responded, "Because of the stresses in my life, I guess so. All the stresses in my life are because I'm a Black woman." Pam explained all of the things that Black women have to contend with that may contribute to acquiring fibroids:

Because we go through so much! Black women go through so much! I mean with our men, with our families, with our children, we are superwomen. We try to hold it all together, and I just think we go through so much, and we have it, I think, I don't want to say harder than other women, but our lives are just so different . . . most of us, we will work 2 and 3 jobs to take care of our families. We do what we feel we have to do to make our home a home, and make sure our kids have food to eat. And I think that's why we have such difficulty with it. We do things we shouldn't be doing. We're carrying the load of the father and the mother, and the maintenance man, and the repairman, the financier, everything. And I think that we hold a lot in, and I think it tells in the illnesses that present themselves in our bodies. I really believe that.

Pam's account of how different Black women are from other women emphasizes the unique social position of Black women in the United States. The lifestyles Black women lead as described by Pam have major implications for Black women's health. For many of these women, the consequences of their

identified race/gendered burdens and their social location in society, concretely impact their health. Specifically, these added burdens and challenges manifest themselves in fibroids.

## CONCLUSION

While fibroids are considered to be “benign tumors in the uterus,” women defined them in relation to their symptoms, and their emotional and functional impact. Through their narratives, respondents illustrated that the reasons Black women are disproportionately affected by fibroids are socially constructed, and based on their lived experiences and struggles as Black women in the United States. For several women in this study, the condition of fibroids has become normalized for Black women from generation to generation. Their beliefs about why Black women are more adversely impacted by fibroids are explained through their race-gendered histories, unique stressors of Black womanhood, the food that they consume, and the combinations of multiple factors. Black women understood fibroids to develop from structural factors such as the environments in which they live, which is commensurate with a social constructionist perspective of illness. The women also explained how fibroids represent physical manifestations of stress and emotions that come from their race-gendered life experiences.

This study underscores how Black women’s experiences based on their race, class, and gendered roles, influence their conceptualizations about fibroids. By using a Black feminist epistemology and assessing knowledge claims from Black women who have fibroids, the study provides context for epidemiologists and offers a different perspective for sociologists. Shim’s research on CVD expressed the importance of lay-science interactions, “As ideologies of biomedicine and health increasingly implicate practices of everyday life, it is critical to examine how epidemiological and lay knowledge’s both participate in shaping how we understand the connections between race and health” (Shim 2005: 406). As biomedical research cannot determine the etiology of fibroids or adequately explain the disparities found between Black and other women, these women’s ideas about fibroid etiology contribute to shaping the connection between race and fibroids.

## CHAPTER 5: EXPERIENCING UTERINE FIBROIDS

### INTRODUCTION

Previous research on the illness experience has explored illness from the patient's perspective (Glaser and Strauss 1965), the subjective day-to-day experiences with chronic illness (Charmaz 1991), and how individuals engage in identity reconstruction in the face of illness (Bury 1982). This type of research reveals what medical professionals cannot, about what it means to be ill, and underscores the meaning of illness, the social location of people experiencing the illness, and the strategies used for coping (Conrad 1987). Given that Black women socially construct their thoughts about what fibroids are and why they have them, a constructionist approach to the analysis of the illness experience is relevant for understanding how fibroids impact their lives. Conrad and Barker state that this approach examines the personal and social meanings of illness, and explores how it is managed in the social context that sufferers inhabit (Conrad and Barker 2010). However, Timmermans and Haas (2008) advocate for sociologists to enhance their analyses by also grounding the illness narrative in the biology of the disease being studied; essentially sociologists should take into consideration how the severity, symptoms, and etiology is different for every person with the same disease.

In this chapter, I take the approach suggested by Timmermans and Hass (2008) and consider the diversity in severity of symptoms and coping mechanisms associated with fibroids. Throughout the interviews, women discussed the several symptoms that were associated with their fibroids, including: frequent urination from fibroids pressing on the bladder, unexpected bleeding between menstrual cycles, general discomfort from abdominal protrusion, and anemia. However, the most pervasive symptoms were heavy bleeding and pain. Social factors such as race/ethnicity, class, education, and so on can influence the type of coping strategies that are employed to deal with fibroids. This chapter explores women's experiences of fibroids focusing on the impact of fibroids on quality of life, and coping by "keeping it moving."

## QUALITY OF LIFE

Several studies have documented the diminished quality of life for women with uterine fibroids through quantitative studies and surveys (Williams et al. 2006). One of the most extensively discussed topics among participants was the impact of the pain and heavy bleeding on their lives. Symptoms of fibroids can be both chronic and acute, debilitating one day and manageable the next, and influence very important aspects of women's lives. Throughout this section, women describe the emotional toll that fibroids took on their psyche, the impact fibroids had on their fertility, and their lifestyles. More often than not the impact of fibroids intersected at many levels, and varied depending on severity of symptoms.

### *Lifestyle*

Fibroids affected women's lifestyles in many ways, disrupting work, social time, vacations, and sex with their partners. A majority of women resolved to go to work despite the heavy bleeding and intense pain; however there were some instances in which the women did not go to work or their work was impacted by their fibroids. Halle's pain was so bad, "It affected me going to work around the time of my menstrual cycle 'cause I was in so much pain, I would be doubled over." The pain associated with a "normal" menstrual cycle usually would not prohibit one from going to work, but having fibroids causes irregular symptoms that can be unbearable.

Zoe also talked about how her extreme pain impacted her ability to go to work sometimes and she avoided missing work because people were not accepting of the fact that fibroids affect the menstrual cycle differently than that of the average woman:

If I have to call out, I'll call out and say I'm not feeling well, therefore I won't be in. But on occasions where I have shared, some women who have experience or dealt with problems with fibroids are symptomatic, and some aren't. So when I kind of became aware of that, it's like well you don't need to share, they don't need to know why you're not coming in because everyone isn't as sympathetic towards the situation. That's been the common sentiment, or it's cramps, just take some medicine and it will be okay. You're like, I can't walk, I can't stand up right, so it's more than just taking some medicine.

Zoe's account reflects a lack of understanding from her coworkers, and led her to conceal menstrual problems, similar to Seear's work (2009). Seear (2009) examined how women minimize pain associated with endometriosis and fail to disclose menstrual problems to avoid stigma, and social sanctions. In Zoe's case, while trying to avoid social sanction for missing work, she shares with some how the fibroids affect her. Zoe appears to be socially sanctioned by her coworkers not only because they have a lack of understanding about fibroids, but they also minimize pain and other symptoms associated with the menstrual cycle in general. When asked how she felt about this, she went on to say, "I think it's insensitive; lack of information on their part. Highly inappropriate, because you can't tell me how I should feel at any given point in time based on any condition." Her sentiments speak to Timmerman and Haas's (2008) point about the importance of understanding that the range of severity in symptoms matters, and not every person with the same disease will experience it in the same way.

Zoe's workday involved sitting behind a computer most of the day, or in meetings. Women's work-life experiences with fibroid symptoms vary by type of occupation and field. For example Nell, who is an OB/GYN nurse, described a scenario where her fibroid symptoms impacted her ability to come to work one day:

I had heavy periods, cramps. I even had an episode where I had to call off of work because I was bleeding too much. I couldn't stand up, blood everywhere. I'm like how do you call your boss and say; I'm not coming to work, I can't come today. You know they not supposed to ask you why, right, but my boss was the sweetest thing ever, okay. And she never asked me, she never said, "why are you calling out?" but you always told her why. I worked at OB/GYN. So, [mocking her boss] "how in the hell you calling me telling me you bleeding too much you don't know how to fix yourself?" No I can't fix myself. So I've had episodes where the bleeding was like disgusting, that I had to go to the doctor for that.

On this particular occasion, she had to go to the hospital because the bleeding was so bad, and they gave her some type of medication to stop it. Nell's background in working with OB/GYN made her feel embarrassed about calling out for gynecological problems and not being able to manage the heavy bleeding on her own. Calling out from work did not occur on a regular basis for Nell. Despite her



supervisor being more knowledgeable about gynecological conditions, which is contrary to Zoe's coworkers, there was still an expectation for her to "conceal" and come to work.

Several women in the study went to work regardless of the symptoms associated with their fibroids, but were still affected by the symptoms while at work like Loretta and Lisa. Loretta experienced very heavy bleeding. As a nurse she explained how difficult it was to do her job while on her cycle:

I hate those things. I mean gosh, they're just terrible! They just change your whole life. You can't wear white. Do you know how difficult it was to work, and running to the bathroom every 15 minutes on those days that the cycle is heavy and I mean it's just gross.

Her work life was greatly affected by her experiences with fibroids. Nursing requires a lot of walking, moving around, and attentiveness to patients. So, heading to the bathroom every 15 minutes due to heavy bleeding is a lot to deal with for a nurse working in a busy hospital. Loretta chose to be interviewed at the end of her shift at work, and I could not help but notice that she and all the other nurses were wearing white. The following conversation ensued when I asked her if she had to always wear white at work:

Loretta: We do as nurses, if you're an LPN or an RN, you have to wear white; it's a requirement.

R: So you had to wear white, even when you were on your cycle?

Loretta: Yes. Well there were days that I um, I would always bring an extra change of clothing with me, or have it in my locker . . . If it was a heavy day, sometimes I'd wear scrubs, the different colored scrubs; the dark green scrubs. I've done that before. We're not supposed to but the fibroids weren't supposed to be there you know. So, I did compensate some days, particularly heavy days.

Not only was Loretta affected by the heavy bleeding at work and continuously having to go to the bathroom throughout her shift, she also could not comply with the dress code at work. Fortunately, she had an understanding supervisor who could actually relate to her situation because she also had fibroids; but her experiences at work may have been different if she had a male supervisor or someone who did not understand the complexities of fibroid symptoms.

Lisa graphically talked about the magnitude of her heavy bleeding before her myomectomy and how it impacted her life and work, “It was like when I stand up, and it was literally like someone, I’m sorry to be graphic, took a shotgun and shot me up there because I couldn’t stand up without blood gushing out.” She further elaborated on how her symptoms affected her quality of life and work specifically:

Well, I can’t do anything when I come on my cycle. You know, if I had to come to work, I have to stay in the office all day. If I could go for the day I try to, but I don’t go in, because I can’t. Just physically, it just feels disgusting. Honestly it does, just so much. It definitely affects my quality of life, even if it’s just a few days out of that month; it’s just like when it comes, you’re just dreading it.

She also described how fibroids have caused some embarrassing moments for her at work, like blood on a coworker’s chair, and fatigue from anemia. Her symptoms have affected her so greatly that she would prefer not to go to work during her times of heavy bleeding, or anywhere else for that matter. Even though Lisa’s job requires her to sit at a desk most of the day, her energy and productivity was decreased because of her anemia. After her myomectomy, while the bleeding had improved, the fibroids grew back and Lisa is again experiencing heavy bleeding. As a coping strategy, she explained how her wearing of Depends (adult diapers) allows her to deal with the heavy bleeding in a stress free way. When asked how she felt about being 36 years old and buying Depends, Lisa said,

I know, isn’t that horrible? But you know, I always make it seem like, I throw them in there like it’s no problem, like it’s my mother’s, like it’s not for me. So I think I take that approach. People are like surely that’s not for her, so you know, you do it carefree casually. You know, not like all timid and throwing it in the cart. Yeah, so I think that’s how I approach it.

Lisa’s situation illustrates how her life was impacted by her monthly episodes of extremely heavy bleeding to the point where pads and tampons, which would suffice for the average woman, are no longer sufficient for her during bouts of heavy bleeding. For her, having to buy Depends at 36 is unnatural. It is a great inconvenience and perfect illustration of how fibroids can take something as normal as being able to wear regular underwear during one’s menstrual cycle to having to wear

Depends so as not to bleed everywhere. It also forces her to develop coping strategies to manage the potential embarrassment of buying adult diapers.

Outside of work, women had to make changes in other aspects of their lives in order to accommodate severe fibroid symptoms. Like Lisa, Chandra, who is 46, also found comfort in wearing Depends to cope with the heavy bleeding and leaking, “Depends were helping because I was always bleeding out from the tampons and the pads. Depends were helping for it to not go through my clothes. And I had to sleep with Depends on.” Having to alter normal activities such as wearing cotton underwear to having to wear adult diapers – even while sleeping – is problematic and a reflection of how severe symptoms from fibroids can take away a woman’s confidence in her ability to manage her fibroid symptoms. With both Lisa and Chandra, the concept of maintaining menstrual etiquette applies. Menstrual etiquette refers to the act of women concealing their menstruation to avoid stigma (Seear 2009). These women go to great lengths to conceal their cycle and avoid potential embarrassments due to heavy bleeding, by wearing Depends.

Some women modified their socializing during their menstrual cycles. Before her first surgery Taraji experienced excessive bleeding, and when the fibroids came back she dealt with heavy bleeding and an enlarged uterus. She described how her periods had changed after she developed fibroids, “I had been having really bad periods and like seriously, seriously, bleeding for days, and days, and days. I think the longest time I bled was like 40 days straight. It wasn’t of course heavy heavy bleeding every day, but it was bleeding nonetheless.” Excess bleeding can cause anemia and decreased energy levels, which can impact one’s demeanor. In addition to being tired all the time, and having to both work and go to school, she acknowledged how other aspects of her life were affected by the heavy bleeding, “I socialized less, I did not work out, I was lethargic all the time, and when I would have my period, I was not to be fucked with.” Fibroid symptoms are not always associated with menstruation as evidenced by her feelings of lethargy, and Taraji has no problem letting her social circle know what is going on with

her during her cycle. Taraji's experiences reflect the impact of fibroids on her routine activities: "It was really ruining my quality of life."

When Debbi was asked to rate the overall impact that fibroids had on her life on a scale of 1-10 (with 10 being the worst), she replied, "I'm going to say . . . I want to say this, as far as outside of my cycle, no interruptions. But during the time of my cycle it was a 10. It totally disrupted my life. When I was on my cycle life was really . . . I was almost unable to do anything." She explained how her coming and going was restricted by pain, and heavy bleeding:

Absolutely! When I was on my cycle I would not go out. I would not go out in any kind of social setting for fear that I would bleed through my clothes. Even if it was a little bit, I didn't want to. And then the pain also; if I didn't have to go to work or do anything, I'm in bed, I'm not getting out of bed, I'm taking my Motrin until that pain goes away. So I couldn't, I really had no active social life during the times I was on my menstrual cycle.

In terms of the severity of her symptoms, Debbi described her cycle as, "Painful, painful. . . . I took Motrin, and sometimes I couldn't even go to work the pain was so bad, even with the Motrin. It was just excruciating. It was like someone put a bowling ball on my uterus and just, [laugh] started pressing down on it [laughing]." For Debbi, when she was symptomatic, fibroids completely disrupted her normal routines. Women who have severe symptoms from fibroids have to make enormous concessions in their lives to accommodate for fibroids. For women like Debbi, Taraji, and Zoe, these concessions included missing work, meaning that fibroids take both a social and a professional toll as severe symptoms can lead to absenteeism.

Loretta rated the overall impact of fibroids on her life as a 10 out of 10 because of the spontaneous heavy bleeding she experienced: "It changed my whole life, as far as where I could go, what I could do, when I could do it. Planning trips around fibroids, visitations around fibroids. Take vacation time so I'd be at home when it comes on, you know that kind of thing. It changed it a whole heap." Loretta's use of vacation time from work is very telling of how impactful fibroids can be on one's life. Additionally, using vacation time instead of sick time implies that the symptoms of fibroids do not

relegate someone to a “sick role.” Whether this decision was based on her own ideas about the use of sick time or her supervisor was beyond the scope of our conversation, but should be considered given that her symptoms were severe enough for her to stay home from work. With regard to going on vacation and taking trips, essentially, Loretta had to plan her life around her symptoms of fibroids. Her heavy bleeding had become spontaneous and Loretta usually planned around symptoms as they occurred.

Robin however, was fortunate to know when her cycle was coming and planned around her symptoms: “It definitely affects activities, and I try to do things to work around. I’m like ok, I’m on a cruise, I’ll be on my period, so I got to do this, this, and this, and prepare this way for vacations. Always have to put vacations around that time, dang it, or holidays. It’s very unfortunate.” Concealing the impact of fibroids becomes more difficult when vacation planning involves other people. Robin discussed an instance where she had to disclose her fibroid symptoms to a friend during Mardi Gras because she was not able to participate in the festivities that day; she also needed her friend to get medication for her. As expressed by women in this study, it is sometimes difficult to plan spontaneous activities or modify pre-planned activities around symptoms of fibroids.

Pain was not always simultaneously experienced during the menstrual cycle. Lynn describes the pain she experienced during sexual intercourse when she talked about her symptoms, “Pain, pain, bleeding, discharge, discharge, pain with sex. Pain, pain, pain with sex, discharge, and extra extra extra amount of bleeding, and anemia.” Fibroids cause more than heavy pleading and extreme pain during the menstrual cycle. They are tumors in the uterus that are hard, occupy space, can press on other organs as they grow; they can also grow in parts of the uterus, like the cervix, which can disrupt other bodily functions and activities. For example sexual intercourse can be extremely painful for women like Lynn with large fibroids. In addition to having problems during her cycle, Lynn also had to cope with and adjust to having pain during intercourse with her husband. Thus, the pain of fibroids affected not only social and professional lives, but intimate interactions and basic aspects of women’s lives as well.

In addition to managing symptoms of heavy bleeding, Eartha experienced other symptoms that caused her to restructure her daily routines. A major symptom for Eartha was the constant pressure on her bladder from the fibroids. She talked about how she has to adjust her life around bathrooms, “But it’s one of those things where like if I go somewhere I almost always make sure I know where the bathrooms are located. Whether my cycle’s here or whether or not I just know I’m going to have to use the bathroom within like 20 minutes if I drink liquid of any sort.” Going to the bathroom is a normal part of everyone’s life, and orienting her life around the location of the nearest restroom underscores how fibroids shape, and significantly alter women’s lives. Additionally, not being able to sit in an hour-long meeting without having to go to the bathroom, and having to limit liquid intake, is very disruptive to daily functioning.

Cicely talked about how her symptoms from fibroids put a strain on life with her family. Cicely not only suffered from excessive heavy bleeding, but also unfortunately suffered from breakthrough bleeding episodes where she rarely knew when she was going to bleed because her cycle was so irregular. The heavy bleeding affected her intimacy with her husband, activities with her daughter, and work. She explained, “I didn’t want to be bothered with anybody. . . . I was married and I did have problems with our relationship, because I kind of think he felt like, ‘who bleeds like that?’ . . . I wouldn’t say it caused the end of it, no; but there were issues.” She did end up getting a divorce, but she explained they had other issues as well, so she could not attribute it to her symptoms. There were implications for her spontaneous bleeding episodes that were not isolated to her husband, but her daughter, and everyday life:

Oh, I couldn’t do much of nothing. I was so tired all the time. I could barely just come to work and make a day, then I was just ready to go home and lay down. And I did nothing outside of work because I was scared I was going to have an episode. Even going to church, I was scared to go and sit in there. I was really scared because I didn’t want to be embarrassed. At the time, my daughter started with her teenage antics; so I had to take her to a therapist. And I remember sitting in his office talking. I remember saying to myself, and this is bad because I should have been focusing on what’s going on, but saying don’t do this now, because I know this is going to happen. And sure enough [she

had an episode during the session] And he [the therapist] said don't worry about it, don't worry about it, we'll take care of it, because I was crying and saying I'm sorry and all that kind of stuff.

Cicely literally could not have a normal life because she could not plan anything due to her episodes. Throughout our conversation she shared several embarrassing moments that occurred in public places that led her to stay at home unless absolutely necessary. She was limited to the activities that she could do with her daughter because she did not want to embarrass her as well, but at the same time did not want to miss out on important things in her life. One such activity was when she and her daughter were in the therapist office together. Not wanting to take away from the time and attention needed for her daughter, she was constantly worried about an episode happening, and it eventually did, further contributing to an already problematic situation. All aspects of her life were completely disrupted because of her fibroids, changing the normal life trajectory she may have imagined for herself. Despite their efforts to conceal their symptoms of fibroids, the women's experiences with the condition are individual and social; individual because the symptoms impact their personal lifestyles, and social because their interactions with others are influenced by symptoms as well.

### *Stress of Having Fibroids*

In the study of women with fibroids in London, discussed in chapter two, the authors found that half of the respondents had clinical levels of anxiety and 22 percent were clinically depressed (Nichols et al. 2004). Considering that Black women already have unique stressors in life as discussed in the previous chapter, it is important to consider how fibroids impact Black women's mental well-being. For Elise, experiencing fibroids and the symptoms was "an inconvenience, it was embarrassing, it was hard to understand how that much blood was coming out of me, and it was very frustrating." Other women were overcome with emotions of frustration and sometimes tears when embarrassing episodes happened or when symptoms impacted their regular activities.

Earth's heavy bleeding led to some embarrassing moments as she described below:

I messed up the chair once, which I cried about. Thankfully I was the only one that knew it. And I had, I think I had my jacket; so, I was able to put that around my waist. After the meeting was over and the conference room was closed, I went back with soap and water and tried to clean out the chair.

Symptoms that were out of her control, and difficult to manage were distressing to the point of tears. It is likely that nobody noticed what happened in the chair that day, however Eartha constantly worries about it happening again. Eartha's account reveals the level of frustration that is caused by having severe symptoms of fibroids that sometimes cannot be concealed. Fibroids were constantly on Eartha's mind, as she always had to go to the bathroom because of the bladder pressure and worrying about bleeding out whenever she was on her cycle.

Jasmine revealed similar sentiments. On one occasion, she had to return home after just arriving at work due to a spontaneous bleeding episode en route:

I was so mad, I cried all the way home. You know how you get so frustrated, you cry? So it was more out of frustration than anything else, because it came on and I wasn't even cramping. Which was unusual, I know when it's coming, and this particular time I hadn't been cramping or anything, and it was just there. So I was so frustrated, just like mad at the world. I was like this is crazy! It started freaking me out, and I was like this thing just isn't working and it's not good. Not good.

It is not just stressful to have to deal with the symptoms but to deal also with how instances like this require restructuring of one's life. Jasmine was so upset that she cried in anger for having to deal with such problematic and unpredictable symptoms associated with fibroids. Experiences of constant frustration with fibroids can have a great impact on one's life.

It is important to know that women also think about their fibroids between menstrual cycles and the stress they cause is not just associated with their symptoms of heavy bleeding and painful cramps. As Cicely and Jasmine's experiences have revealed, they worried about having spontaneous episodes for which they were not prepared. When asked if she thought about having fibroids between her cycles, Loretta explained: "[laugh] yeah I thought about them in that I didn't know when they would come back on. Oh God, is this the day? So I always had to wear panty shield or something like that." She



not only thought about the spontaneous bleeding between her cycles, even when she was not on her cycle, she began to live a life of constant paranoia by wearing a panty liner every day.

Leliti also describes how her psyche was altered at the thought of her menstrual cycle starting, “Psychologically, when I’m getting towards the next cycle, I start thinking of it. My mind is focused, that is all I think of and what I’m going to go through. It’s terrible, it’s terrible . . . I get in this kind of panic and fear about it.” Leleti’s panic and fear comes from the heavy bleeding she experiences and the fear of bleeding through her clothes. Panic and fear are not minor feelings for anyone to have, let alone roughly once a month for a considerable part of your life can have an impact on one’s quality of life.

Constantly having fibroids or their symptoms on their mind is very frustrating as Halle also shared, “Well most, if anything it’s just constantly on your mind. For me, I was thinking this thing is growing inside of me, getting bigger and bigger.” Her symptoms were heavy bleeding and extreme pain. Knowing that something foreign was growing inside of her that she could not control was a daily reminder of her fibroids, which is stressful.

When asked what had been the most troubling concern or issue for her regarding having fibroids, Patience talked about their hindering nature and them being a source of frustration:

I think it’s debilitating nature. It adds additional stress on top of what the stress already produced. It’s just so, it can cause you to be weary, gosh, probably even depressed that they might not have many options to address it. I remember times just feeling so frustrated I guess, and weary that it was coming, and that it was going to be here. I just wished it could go away.

The psychological impact of having fibroids is significant as indicated by the fact that physical symptoms, which were pretty severe for Patience, did not represent the most troubling concern about having fibroids. Despite the severity of their symptoms, several women were affected by the constant thought of having fibroids, the stress the fibroids caused, and the constant worrying and dreading of pain. The combination of the physical and emotional stress of having fibroids impacts the quality of life for women in this study.

### *Fertility and Pregnancy*

For the most part, the impact of fibroids on fertility and pregnancy were often tied to respondents' emotions and thoughts about having fibroids. Emotions varied for women when they realized they could not have children, or the lives of their children in utero were threatened. Here Zoe reflects about her realization:

Right now, at 35 it saddens me. If you would have asked me this 5 years ago, I would say, Oh it is what it is, you deal with it. But now as my focus in life changes and you start thinking about, okay family and family unit, and what does that really look like, what does that really mean, and how are you able to contribute to that? It saddens me that I won't be able to carry a child. And I used to say, oh I don't want children and people would say that's not normal but as I think about it, it was more so an emotional defense mechanism. I know that I can't have children, so why long for something that you can't produce. So right now at this stage of my life, it saddens me.

The fact that Zoe will no longer be able to have children has greatly impacted her life, despite the defense mechanism she used to mask her desire for children. There was a difference between wanting children and not being able to have children; she could deal with knowing that she potentially still had the option. However, now knowing that she definitely cannot have children, whether she wanted them or not, brings out her true feelings about her desire for motherhood and the impact that fibroids have had on her life overall.

Fibroids adversely affected the fertility of seven women in the sample who tried to conceive, but were unsuccessful or never had the chance because of the treatment decision they chose. Several women identified these negative effects on reproduction as the most difficult aspect of having fibroids. When asked to rate the overall impact of fibroids on her life on a scale of 1-10, Wendy, aged 39, replied, "That's hard. Reason being is that if I had to say between the fibroids and the endometriosis, with me not being able to have kids, then I would say a 10." Fibroids and endometriosis both threaten the ability to have children. Despite ultimately having a hysterectomy, the two conditions combined would not have allowed her to get pregnant. Wendy was a single woman who expressed not wanting to start a family until she was married, so she had not had the opportunity to try and get pregnant at an earlier

age.

For several years, Lena, aged 36, and her former husband tried to conceive but were unable to get pregnant prior to their divorce:

It was like an emotional rollercoaster for me. And I don't think anybody ever talks about the men involved, but even from other times, my ex-husband's point of view, it was just so much emotion. During the trying to have a baby process, if I didn't get a period, lets go buy the pregnancy test, false alarm. Through the, "oh my gosh she's bleeding for a year, what are we going to do? What do you mean count the months until we have sex? We can't, because she's doing this!"

At times throughout the interview she was teary eyed as she discussed the emotions of not being able to bear her own children, which had a major impact on her life. Having children is a major part of Lena's life plans, but the type and location of her fibroids would not allow her to get pregnant. Her experiences with trying to conceive were further complicated by the symptoms associated with her fibroids; constant bleeding, irregular ovulation, and unbearable pain.

One of the most powerful statements about infertility as a result of fibroids came from Beverly who likened her inability to have children to having a disease: "The hardest thing in the world, and I said this to my sister, I said, 'I'd rather tell someone that I have AIDS than that I don't have children.' That's sick isn't it? That's how painful it is. So, I tend not to deal with people." Beverly was essentially devastated by not being able to have children. She called herself a loner and limited her social life because she does not want to reveal her inability to have children. Equating a stigmatizing, incurable disease with the inability to have children is a reflection of how important motherhood was for Beverly, and how her life trajectory changed as a result of fibroids.

For Josephine, who was told in her twenties she would not be able to have children even if she did not have the hysterectomy (that she later had), her life was impacted at many levels. She was emotionally upset by the fact that her fibroids took her ability to have children and she explained how she stopped trying to date:

You know you just don't get involved. You know I found myself not getting involved [with men]. Um because for one I knew it wasn't going to work. You know I'm always

going to have this problem. . . . that's not the way life was supposed to be. And I think you know when I talked to my grandparents, you know you find someone, you get married, you have kids, and I guess I knew it wasn't going to happen.

Despite its non-cancerous nature and most often non-life threatening symptoms, fibroids are far from benign if it can take away a woman's ability to have children. There are biological consequences that have social implications for these women's lives. Not only do fibroids have an effect on relationships because of their symptoms, but infertility also creates a barrier to how women pursue relationships as Josephine explained. Having fibroids involves losing interest in her previous life goals of finding a husband and having children.

The last part of this section moves beyond fertility to will focus on three women whose childbirth and pregnancy experiences were impacted by fibroids. Lynn, Lisa, and Leleti all delivered healthy full term babies, but having fibroids resulted in varied pregnancy and childbirth circumstances. Prior to having children, Lynn and Lisa were advised by their gynecologists to have their fibroids removed in order to prevent complicated pregnancies. Ironically however, both women found out they were pregnant before they could have their surgeries. Lisa delivered a full term baby girl of eight pounds via Cesarean section, but her pregnancy was very painful, "I don't know how she [Lisa's baby] was able to sustain and develop normally and live and just coexist with those things, because they got huge . . . I was on pain medication I think like 2 or 3 times at the beginning of pregnancy because of the pain. Like I couldn't even . . . it was so severe."

Lynn also experienced pain with her pregnancy, and bleeding among other things. The doctors thought she would miscarry or go into premature labor and deliver early:

I had preterm labor maybe about 5 times. Every time I went into the . . . doctor's office, they always had to give me extra fluids. I think I was on tributylene on a regular basis and aspirin . . . By the time I'm like 3 months pregnant, I look like I'm like 6 months pregnant.

Once she went into labor she had minor complications with rapid labor, but ended up pushing for less than 10 minutes to deliver her daughter vaginally. For Lisa, the impact on her pregnancy was the biggest challenge associated with having fibroids, "my child could have [been] harmed. . . . I could have died."

Leleti also was not trying to conceive at the time, but had just learned of her fibroids when she became pregnant. She experienced bleeding during the first 3-4 months and then her pregnancy was stabilized. Her experience in the Nigerian delivery room was a little unnerving:

And when she [her daughter] came out, I remember the doctor kept on saying something that, he was talking to the nurse, and saying, "I don't understand what this is"; clots came out. He kept telling the nurse, "I don't know why she's bleeding so much and a lot of clots are coming out." But he kept on. They had to go and get medication, which was around 3 or 4 am. He had to go around knocking on pharmacy door looking for a medication to do the . . . maybe it was a plasma expander, I don't know what it was. I knew that I had bled so much and I had a lot of clots, which I believed, I just believed, that might have been part of these fibroids came out at that time.

Leleti was very lucky, as she could have died in this scenario. Being in a Nigerian hospital, as she explained at one point during her interview, was not the safest place to be, especially in the care of junior level doctors who are "terrible." The fact that she had fibroids and was having a vaginal delivery was difficult enough, but to add to it the uncertainty of being in a delivery room in Nigeria was an added layer of risk. Fortunately for Leleti, her husband knew doctors in the medical community and senior level doctors usually treated her, but if she were from a lower class status with less social capital, the outcome could have been very different.

The quality of life for women in this study was greatly impacted by the symptoms and stress associated with having fibroids. Having fibroids affected women's ability to have children and made pregnancies frightening. Moreover, fibroids disrupted intimacy and relationships, occupied daily thoughts (especially during menstrual cycles), and caused embarrassment, fatigue, and emotional distress. Examining the social meaning of living with fibroids, while taking into consideration the severity of symptoms, allows for a better understanding of what it means for Black women to have this condition.

#### "KEEPING IT MOVING"

Given the impact of fibroids on Black women's lives, what are these women doing on a day-to-day basis to cope with this condition? A lot of them are sucking it up and just pushing through, they are

“keeping it moving.” The “keep it moving” narrative was common among women with regard to coping strategies employed for fibroids (N=16). Most women in this study did not embody Parsons’ “sick-role” (Parsons 1951), mainly because people with fibroids have varying levels of debilitation associated with their symptoms. Recall that falling into the “sick-role” involves a “state of disturbance in the ‘normal’ functioning of the total human individual” (Parsons 1951:430). While the symptoms might have been painful and embarrassing, and altered their normal functioning, women did not allow themselves to be completely inhibited by fibroids. For some women, as will be discussed in chapter six, they did not fall into the sick-role because they did not allow their condition to be policed by the medical profession or comply with doctor’s recommended treatments. They also did not embrace a sick-role because many women did not let their symptoms control their life. Women continued to go to work because they had to, whether it was because of money or to combat negative stereotypes about Black women in the workplace. The “keep it moving” narrative was also prevalent among women whose symptoms were not as disruptive.

Robin who had been recently diagnosed, is fairly young at age 27, not ready for children, and not ready to make a decision about treatment, just pushes through: “I get to the point where I just take some Midol, Advil, whatever I have available and just keep it moving. But it’s definitely a nuisance to be in pain and work through it.” Robin reached a level where she did not really worry about it and wasn’t overly concerned, “Yes I have fibroids, yes it’s so painful, but I guess it’s just something that I have to deal with.” There is nothing for her to do in her case but to keep it moving.

Pam is an office manager in an oncology department. When her symptoms got bad at work she said, “[I] just deal with it. Get a cup of hot tea. We have tea here [at work]. Just get a cup of hot tea and just deal with it. I don’t keep my mind on it. That’s it.” There are implications for how Black women represent themselves at work, which can influence how Black women cope with fibroids in that setting. For example, Black women have been labeled as tardy, lazy in the workplace, having a tendency to lie,

and other stereotypes that vary by class and occupation (Kennelly 1999, Harvey Wingfield 2007, 2011). While Pam's "just dealing with it" and not wanting to call out for work may not imply a class issue or her need for money, her actions exist in the context of gendered racism in the workplace.

Other women strived to maintain their pre-fibroid identities or their symptom-free selves, which is similar to what has been found in previous studies on experiences with chronic illnesses. They are trying to avoid a "loss of self" (Charmaz 1991) due to their fibroids and employ tactics to reconstruct or maintain life despite the biological disruption of fibroids (Bury 1982; Williams 1984). Zoe, who has a high tolerance for discomfort, is also resilient and explains how she maintains her identity as an athlete and physical trainer:

Well I think I also said I have a high tolerance for discomfort. So while I'm aware that I'm in pain, I don't stop performing because I'm in pain. So, when you look at it from that perspective, I'm always in pain. Even through my practice, if you will, across the spectrum from yoga to whatever, I just don't let it hinder me from any form of activity, until recently; just because it's such an inherent part of who I am. So that's the point . . . the things that I do are not just activities, they're me. It's what defines me; it's basically my make up. So I choose not to let the fibroids hinder me from continuing to be . . . I don't like to feel like I am being subjected to a condition. . . . this is my body and I will not just basically have a pity party for myself. I guess it's another coping mechanism. So I'm aware of the discomfort, I'm aware of the pain. It's definitely always there; I just make a very concerted choice. And there are some days I'm like, "oh gosh, I can't walk."

Zoe did not maintain her athlete identity for income purposes (as this is a side career and not her main source of income), but she did it for herself. Thus, allowing fibroids to take over her life meant undermining her sense of self, which she would not let happen.

For some women like Eartha, the "keep it moving" mentality has deep cultural roots that are based upon conceptualizations of illness from childhood. Eartha described her extremely low energy level and heavy bleeding, and reported not staying home when her symptoms were at their worst. Her decisions were based not only on her loyalty to her job, but also her socializations of healthcare and illness:

If I were sick or had a cold or whatever [as a child], we'd take medicine and still go to school. You were darn near about to half-way die if you did a sick day in my house.

That's the only reason you'd be allowed to stay home, like if you ended up going to the ER or something, you were really sick to stay home.

This mentality has stuck with Eartha over the course of her life and she did not take off work because she was not able, but because she did not want to miss work. Eartha's socialization of "what is sick," is rooted in her childhood and how her parents ran their household. You have to be "really sick" to stay home, translates to you have to be "really sick" to stay home from work. Having fibroids does not constitute sickness, so Eartha takes her fibroid symptoms as they come, and keeps it moving.

Eartha's not wanting to miss work was a reflection of her socialization, whereas Taraji could not miss work because there was no other option. She explained, "I think at that time, I didn't have the option of you know, insurance was okay at [her job], but I didn't have the option of being off that much 'cause I didn't really have all of this time off, and I couldn't take time off from school." Taraji's experience reflects a keep it moving strategy that is due to her class status during that time, the type of job that she had, and the fact that she was in school. She had to push through her symptoms and go to work anyway out of necessity to survive and keep her job.

Lastly, at her old law firm, Elise worked in a setting where her Black female identity was under constant surveillance, so she always had to "keep it moving":

It just made everything challenging; I might take a shower three times a day during the times I was really heavily bleeding . . . I just started carrying around wet personal wipes because it just felt like I couldn't get myself clean. . . . It never felt like I knew exactly when it was going to come and if it was coming and I was going to be prepared for it, so I always had a huge purse. But, it always had a package of big feminine supplies in it. I mean, I needed to have all of that. . . . Probably at the worst of it I did have extra underwear somewhere. If not in my purse, then I would always have it in my gym bag, which I would always leave in my car. There was a time when I felt that if I didn't have a change of pants, then I would be left in a bad place . . . I would have an outfit on the back of my door just in case, because it was too much drama to go all the way home, then change, then come back. And like I said, it was kind of about appearances at that firm, because I was the only Black woman they ever had in 100 years of being open. I couldn't be the one that was always running home for something, or to change my clothes, I just couldn't be that. Terribly inconvenient.



Black women have had to contend with upholding nearly perfect attendance, flawless work ethic, and maintaining a healthy work-life balance with their families. For Elise, “keeping it moving” was about establishing and maintaining respect. She not only strived to represent herself in a good light as the first Black women in the law firm, but for those who would come after her. She understood the implications of gendered-racism in the workplace and went through great lengths to ensure that her symptoms of fibroids did not affect with her work.

## CONCLUSION

As demonstrated throughout this chapter, upon diagnosis of fibroids Black women vary in their experiences of fibroids in terms of severity of their symptoms, how their lives are impacted, and how they cope. Fibroids had implications for everyday life that involved women having to restructure their days, and interactions with spouses and others. Because Black women occupy a unique social space in society that is indicative of their race, class, and gendered status, the stress of having fibroids compounds their burden. Lastly, taking into account the everyday lived and unique experiences of Black women contributes to the research on illness experiences because it explains why Black women have a tendency to push through excruciating pain and heavy bleeding despite the impact on their life.

Timmermans and has (2008) have pushed for a sociology of disease that takes into account the meaning of illness and how it might differ based on severity of symptoms. This study examines Black women’s illness experiences using fibroids as an example. The use of a Black feminist epistemology illustrates the ways in which women’s race, class, and gender identities influence their decisions for coping with fibroids and their symptoms.

## CHAPTER 6: TREATMENT DECISIONS

### INTRODUCTION

Brown (1995) posits that constructions of illness are linked to treatment decisions that are made and that the “social construction of treatment is also relevant: choices are made about caregiving on the basis of local medical cultures, race, class, gender, insurance status, and other social variables” (Brown 1995:41). Black women’s history with the medical system, reproductive injustices, and their unique place in society, all provide a unique context in which to examine the decision-making process for treating fibroids. For Black women with fibroids, treatment decisions were based on how severe their symptoms were, and whether or not the women had children, wanted children, or were still deciding. Treatment decisions were also dependent upon respondents’ desire for surgery and wanting a permanent solution. This chapter serves to provide a descriptive overview of the treatment decisions women made and why they made them.

### MAKING THE DECISION

As discussed in the literature review, there are several treatment options available for uterine fibroids. These treatment options include: hysterectomy, myomectomy, Uterine Fibroid Embolization (UFE), endometrial ablation, hormone therapy, Magnetic Resonance Imaging (MRI) - guided focused ultrasound therapy (MRgFUS), complementary and alternative medicine (CAM), and “waiting and seeing” if there is a need for medical intervention (Afua 2002; Evans and Brunsell 2007; Center for Uterine Fibroids 2011). Treatment decisions varied greatly among women in this sample due to the recurring nature of uterine fibroids, the woman’s age, and her willingness to undergo surgery.

Roughly half of the sample (N=16) had undergone some type of myomectomy, whether it was open, laparoscopic, or hysteroscopic. Recall that myomectomies can be either open, laparoscopic, or hysteroscopic. In an open myomectomy, a surgeon makes an abdominal incision and cuts the fibroids out of the uterus. Small abdominal incision points are made during a laparoscopic myomectomy, and

the fibroids are then cut up into small pieces and extracted out of the uterus through a laparoscope using microscopic cameras and other tools. Fibroids can also be removed via a hysteroscopic myomectomy, where the fibroids are extracted through the vaginal opening with the use of a hysteroscope and a camera. A large number of women in this study (N=14) incorporated some type of CAM into their lives to help shrink their fibroids, cope with symptoms, or to help recover after a surgical procedure. However, It is important to note that more than half of the sample combined two or more treatment methods (N=20), with one person having tried five different methods (See Tables 1 and 3).

Table 3. Participant Treatment Decisions

Treatment Decision	N	%
Myomectomy (laparoscopic/open/hysteroscopic)	16	51.6%
Laparoscopic myomectomy	2	6.5%
Open myomectomy	9	29.0%
Hysteroscopic myomectomy	5	16.1%
Complementary and/or Alternative Medicine (CAM)	14	45.2%
Watching/wait and see/waiting for menopause	11	35.5%
Hysterectomy	7	22.6%
Uterine Fibroid Embolization (UFE)	7	22.6%
Other (D&C, laporotomy, laser procedure)	5	16.1%
Partial hysterectomy	3	9.7%
1 treatment method	11	35.5%
2 treatment methods	12	38.7%
3 or more treatment methods	8	25.8%

#### “MY UTERUS HASN’T DONE ITS JOB” – WEIGHING MOTHERHOOD AND FIBROID TREATMENT

One major theme associated with treatment decisions was the weighing of fibroid treatment and the desire to have children. In some cases women had to choose the alleviation of symptoms or having a child, and for others it was and still is a constant negotiation. Research has found that not having had children (nulliparity) increases your risk for fibroids (Ross, Pike, Vessey, et al. 1986), a belief also shared by some women in this study. In this section Black women share their views about preserving fertility while trying to relieve fibroid symptoms. Of the 31 women in this study, nearly half (N=15) did not have children at the time of the study. Of those, most of them (N=12) wanted to have

children; their experiences with fibroids will potentially, are currently, or have previously interfered with their ability to have children.

Robin and Jill both desire to have children, and while they both are married neither of them are ready to start a family. They have both chosen to “wait and see,” and not choose any type of medical intervention since they are not actively trying to conceive. When Robin was asked about the impact of fibroids on her reproductive abilities she said, “I’m not trying to get pregnant right now. But I often wonder, you know, would it affect it? But I’m not sure.” She did not want to take the prescribed birth control because of the side effects she experienced in the past. After looking into some other options and not finding anything amenable to her needs, she decided to treat her pain with Advil, and use condoms to prevent pregnancy. At the time of the interview, Robin did not have health insurance. Had she wanted to choose something surgical, there may have been financial limitations placed on her and her husband.

Some women have other gynecological issues that compound their experiences with fibroids. Jill also has ovarian cysts, which cause her more pain than fibroids, and her doctor prescribed her birth control as a treatment. However, Jill refused to take birth control pills because of her experience in the past, even with the lowest dosage available: “I just felt like really bad, and I did not want to go through that again.” Additionally, her uncle who is a gynecologist advised her of studies showing an increase in fibroid growth with oral contraceptive use. So when Jill was diagnosed with fibroids she chose to “wait and see,” use CAM, and pain killers because she is not currently bothered enough by her fibroids to justify surgery. Doctors continue to prescribe birth control for managing symptoms of fibroids, yet this is not a preferred option by several women as evidenced by Jill and Robin, and studies about fibroids and birth control have had mixed results. Oral contraceptive pills have not consistently been proven to reduce the size of fibroids and there is no evidence this treatment is effective (Stewart 2001; Center for Uterine Fibroids 2011). Jill’s knowledge of the inconsistent studies, and her uncle’s advice, contributed to her “wait and see” approach, as opposed to medical intervention or prescribed birth control.

For other women without children, like Jasmine, Wendy, and Josephine, their desire to wait to have children under optimal conditions (with a husband or life partner) has delayed their actual childbearing. Jasmine (aged 37), who wants but does not yet have children talked about the concern her fibroids have caused:

I've never tried to get pregnant. Of course that's what the doctors ask you, have you tried to get pregnant? No, I'm not married, so of course I haven't tried to get pregnant; but usually, most people would have at least had an oops! So it does concern me, but no . . . I wasn't trying to get pregnant per se, but my ex and I did not use protection and I never got pregnant.

Because Jasmine wants to eventually have children, she has been cautious in her treatment decisions. Her doctor recommended Lupron, which puts a woman in a state of menopause, in which she does not menstruate for six months. During this period of time, fibroids may shrink, estrogen levels may come down, and the woman may be more conducive to conception upon ending the treatment. She was concerned about this because of her age: "I was like, well, first of all, I must have been 36 at the time . . . What happens if I don't bounce back?" Prior to the Lupron recommendation she allowed her doctor to perform a dilation and curettage (D&C) to remove a polyp on the lining of her uterus to help with symptoms, yet her cycle and symptoms became even worse. Ultimately, Jasmine decided to start researching holistic treatment options, "because at this point, modern medicine isn't working, so what will I have to lose by going the holistic route?" Jasmine's treatment decisions were rooted in her desire to have children in the future, but losing trust in her doctor and medical interventions also influenced the types of treatments she allowed.

By her late 30's Wendy had not yet had the opportunity to have children before her hysterectomy. A couple of years prior to her hysterectomy, she had already come to terms with the fact that she would not bear her own children, but she reflected on how she came to her decision despite wanting to be a mother:

So that was my main reasoning in terms of okay, if I don't have kids by this time, then I just kind of figured it wasn't in my cards. . . . okay here it is, I just turned 38, I don't have

a prospect in play . . . 'cause I don't want you to be my baby daddy, I want you to be my husband. . . . the likelihood that I would find someone fall in love, get married, have a baby, all before 40, it was really unlikely. So I was just like, just go on, (laugh) take it out.

When asked about her emotional state before getting the hysterectomy she explained, "I was very emotional before. I even went to a counselor to kind of talk about that because you know it's final, that is final." Wendy, who did not know about her fibroids until her bowel was obstructed by her endometriosis that she also did not know she had, was put on Lupron until her body healed, then Depo shots that she did not continue due to the side effects, followed by birth control pills, which also did not work for her. Until her hysterectomy, she was on Percocet to manage the pain, and then Lupron again just prior to her surgery. She exhausted all possibilities to preserve her fertility and uterus but in the end she was ready for the struggle to end. Wendy was fortunate to have a job that offered good health insurance benefits and allowed her to take off time to recover after her surgery.

Josephine, who struggled with fibroids during the 1970's, had to decide on her treatment during the days when the first and only option for gynecological problems was usually a hysterectomy. Ironically, the 1970's marked the end of sterilization efforts against Black women (Roberts 1997; Washington 2006). Ultimately, she chose to have a hysterectomy at the young age of 29, in exchange for a pain free life. However, even though Josephine had not found someone with whom to start a family, she felt compelled to make a choice:

. . . when I went back to the doctor, he said, 'when are you going to have, when are you going to let us get this out of there?' At that time my mother was with me, and of course I started crying because I didn't want to do it. I still was hoping that they would come up with something that would eventually cure it sooner. And then my mother said, 'well it's just kind of foolish to cry and stuff because you just have to adopt kids.' And it kind of weighed [on me] until I decided I just didn't want to be in pain anymore; that it didn't look like there was any hope. I wish that I had gone maybe to two or three different doctors, but at the time, I just had the one.

Josephine had to contend with several issues all at once, struggling to weigh the benefits of a pain free life, or being able to have children. Since menarche she struggled with the impact this had on her life and not being able to do the things she had dreamed, and eventually relief became her ultimate priority.

At the time of her surgery she had a great job as a flight attendant and very good health insurance, so she did not have to struggle financially to have the operation.

In contrast some women had the opportunity to try and have children but could not conceive due to complications from their fibroids. Zoe, Lena, and Beverly all tried to have children while they were engaged or married. Dorothy is currently married and actively trying to conceive, and Halle, also married, tried for several years but has since given up. For all of these women, their treatment decisions had to be womb saving and fertility preserving.

Zoe (35), who was in her 20's when she tried to conceive and had battled with fibroids since the age of 18, explained she, "had a myomectomy because at the time I was engaged, and my fiancée and I were actively trying to conceive, we knew that the fibroids could potentially cause problems so I went ahead and had the myomectomy to have them removed." The couple was unable to get pregnant, and they eventually did not marry. Subsequently she had a laparoscopic myomectomy, a UFE, and at the time of the interview was in the process of scheduling a partial hysterectomy for the summer. Here she reflects on this decision:

I think that decision came to me; because I remember being 18, in pain, and telling [her doctor's name], 'just take it out, I'm not attached to my uterus.' I guess you should be mindful what you speak into existence right? 'Cause since I was 18, that has literally been my position. And I don't know if it was more so jokingly or just because I've never felt innately maternal, that it's like, I really don't feel a need. What's the purpose or function of it [uterus] anyway? But I think the decision came to me. . . . it's a conscious choice at this point, but it was kind of like the natural choice. I'm okay with it. I think more people are saddened for me, which I don't understand why (laugh). I'm okay with it, and I get the whole idea of, oh you're losing a part of you, and that makes you a woman, but that's not how I define my womanhood. And at times it saddens me, but when I think about it, the only thing it prevents is the ability to carry a child. And I could always . . . there are a lot of children who need to be adopted. So I'm fine with that.

When talking about the impact of fibroids on her life, she said she did not remember what it felt like to be pain free. Despite the extreme pain and above-mentioned detachment from her uterus, Zoe wanted to keep her option of motherhood open through the treatments that she chose. By the time of the interview, after having taken all of those steps to no avail, her struggle to preserve her fertility had come

to an end. She was left feeling sad, not because it would make her feel any less of a woman, but because her *option* of bearing children had been taken away. However, Zoe still hopes to have children through other means.

Lena was diagnosed with a fibroid at age 24 and discovered it when she came off of birth control after 10 years. She and her then husband were unsuccessfully trying to conceive, and she had excruciating periods. Because she had not yet had children, she did not accept the doctor's initial recommendations of hysterectomy: "I didn't want to hear that. And then they came up with another procedure called hysteroscopy. He did that procedure, and that's when he discovered it wasn't multiple, it was one huge one." The surgery was successful but it grew back within the year along with several new fibroids. Since then, the only way to control her symptoms without a hysterectomy was various forms of birth control. Regarding the high dosage birth control pill she now takes that prevents her from having a cycle, she said, "It's working, because I'd rather take that than . . . I just have not come to terms with them . . . You know, I'll be 37 in two months. I have not come to terms with them saying they are going to take out my uterus, I just have not come to terms with it." There is a struggle for women who must weigh whether or not to be pain free versus future motherhood. Lena refused the hysterectomy:

I just feel like there's got to be another option. I just feel like, I don't know, I feel like it's God's gift to me, and who am I to take that away. And if I did something to my body, then it's for me to fix it . . . And I just really, really want to have a baby. I don't know if it's for me, I don't even have a husband, I mean my boyfriend. But I just feel like it's my right. And it's just taking my right away.

She is satisfied with the treatment options she has chosen so far, "Yeah, because . . . The other option is not an option. I'm going to keep saying that."

Halle struggled to make treatment decisions that would ensure her fertility but was not confident that she had made the right choices, because she has been unable to conceive despite the different methods she has tried. When making her decision, she was unsure but saw no other option for relief at the time:



Halle: The option was a myomectomy basically, I could do them hysteroscopically, which I did, or I could have gone through the whole major surgery to have them removed; but I was told that there was no guarantee that they wouldn't come back . . . I was also told that doing the hysteroscopic surgery would lessen my chances of damage because I still wanted to have kids, which was the opposite. It wasn't true, and unfortunately I went through with it because I went on the advice of my OBGYN at that time. . . I later found out she didn't know what the hell she was doing. Unfortunately, I found that out on the operating table.

R: Before or after?

Halle: Well of course I was knocked out so (laugh) for me it was after, but for my husband and my father it was during. She had to stop the surgery because my electrolytes had dropped tremendously and if they didn't stop and get fluids in me right away, I could have died. So in that case, she didn't get the fibroids out and I had to go back for a second surgery a month later to have them removed with the assistance from a specialist. Basically, he did it while she was there.

After having learned that the hysteroscopic myomectomy was not the best procedure for someone wanting to have children, in a last attempt to have a child she found a better doctor and decided to try the open myomectomy in conjunction with working with a fertility specialist, "So my OB/GYN went in to remove all the fibroids and clean everything out . . . and then while he was in there . . . [her fertility specialist's name] came in, who was the fertility specialist to clean and scrape my uterus and get all of the scar tissue off to give me a better option and chance of becoming pregnant." Following the open myomectomy, Halle tried to get pregnant but was not able to conceive, and gave up on her dreams of having children in any capacity be it bearing her own or through surrogacy. Halle's intentions throughout her treatment experience was to preserve her uterus in the best possible way so she could still get pregnant. The hysteroscopic myomectomy, fertility specialists, and open myomectomy was very expensive; \$10,000 came out of her own pocket for the fertility and open myomectomy alone. When asked whether or not the cost was difficult for her, she replied, "Yeah! (laugh) That's cash money, it wasn't insurance that was coming out of my check (laugh)! Yes ma'am, are you kidding? That's why I'm broke now 'cause I spent all my money on that." Despite the cost, having a child was a priority for Halle.

Halle's experience is synonymous with a study by Solberg and colleagues (2009), which found that patients with lower knowledge regarding fibroids (74.4%) had less concordance between their preferences for treatment and their actual treatment choice, than women with higher fibroid knowledge (94.9%). Solberg et. al (2009) did not evaluate knowledge or decision-preference and treatment by race or ethnicity. In fact knowledge of fibroids and treatment options have not been assessed for Black women exclusively outside of this study, yet it is important with regard to the treatment decisions that are made, particularly for those wanting to have children later. Halle, Josephine, and Wendy all expressed not knowing enough about fibroids when they were diagnosed, which directly impacted their treatment decisions and their ability to have children.

Beverly's strong desires for motherhood, mentioned briefly in the last chapter, are so intense that she would rather say she had AIDS than to say she is unable to bear children. A doctor told her early on that there was a possibility she would not be able to bear children and that he should have a hysterectomy, which she has adamantly refused to this day, even at age 62, "Unless I had cancer, I wasn't having a hysterectomy." Over the course of her life, Beverly, who has had a myomectomy, two D&C's, an ablation, and utilized CAM to treat her fibroids, held on to her hopes of motherhood at every obstacle. She admits, "They always wanted to do the hysterectomy. And anybody in as much pain would have opted for the hysterectomy, but I just couldn't do it." When asked why it was so important to her to preserve her uterus she said, "Maybe they would discover something one day. You know, and maybe I'll be the oldest woman to have a child, but hey, keep hope alive. I always said my uterus hasn't done its job, so it's not going anywhere." Beverly's conceptualizations about womanhood are defined by the necessity to bear children and not being able to do this left her feeling incomplete, inadequate as a woman, and humiliated by not being able to have children. Because of her beliefs and strong desire for children, her treatment for fibroids had to include preservation of her uterus no matter what.

At age 40, Dorothy and her husband were ready to start a family, but she found out she had fibroids after trying and not being able to conceive. She explained the plight of Black women, marriage, and having kids from her perspective:

There are a lot of African American women with fibroids that haven't had children. I want to see if that's a reoccurring issue. I think some people just have the predisposition, they just have them. But I think having kids younger, though might not be easy, might have made a difference.

Dorothy also spoke about Black women not being able to find the right person to marry, but because they want to have children, some of her friends, "have just set out to be a single parent. I think they're crazy. That's just me." Dorothy wanted to be married before she had children, which took her longer than expected, and when she did marry they waited to start a family. All of her treatment options were based on the fact that she wanted to have children. She had two hysteroscopic myomectomies since her diagnosis, will soon have another test, another surgery, lose weight, and try other fertilization strategies in hopes of becoming pregnant by the end of the year. Despite all of the barriers Dorothy has faced because of the fibroids, she remains resilient due to her past experiences of having her head sawed open, her eyes sewn shut, and a lumbar puncture: "So I've kind of treated this fibroid just like that. It hasn't stopped me from doing anything, what really triggered me, knowing something was wrong, was when I'm trying to have kids."

Dorothy's account about Black women waiting to have children later and her own desire to be married before children describes an added layer of complexity for Black women and their experiences with fibroids. Her experience, like Wendy and Jasmine, should be considered in the larger context of the decreasing "traditional" family structure in the United States. In 2011, 35.7% of women who gave birth were unmarried; women who were older, had more education, and a higher income, had lower percentages of nonmarital births (Shattuck and Kreider 2013). Unmarried Black mothers had the highest percentage of births, 67.8%, compared to unmarried Asian (11.3%), white (29.2%), Native Hawaiian and Pacific Islander (40.5%), and American Indian/Alaskan native (64.0%) mothers (Shattuck and Kreider

2013). Furthermore, Blacks had the lowest percentage of those who were currently married in 2011, 28.9% compared to the highest, which were Asians (57.9%) and whites (51.6%) (U.S. Census Bureau 2013). These numbers demonstrate that even with increasing levels of education and income, Black women are the least likely group to be married in the United States today.

While Wendy, Jasmine, and Dorothy all earn middle to high levels of income they still expressed concern with being a single Black mother, and not being able to find a husband earlier on in their lives. Their concerns about wanting to be married and having children within a solid marriage or partnership are unique to Black women as other women are not subjected to stereotypes of controlling images identified by Collins (2000). A core theme of Black feminist thought has been to challenge the controlling images of Black women that objectify and manipulate Black womanhood (Collins 2000). Both the 'Black lady' and the 'welfare mother' are relevant in the discussion about the impact of fibroids on Black women, and the affect of delaying motherhood for marriage and economic stability. The 'Black lady' is a woman who stayed in school, worked twice as hard as everyone else, and has achieved much, but has no time for men. Whereas the 'welfare mother' represents a working-class Black woman who is portrayed as avoiding work, collecting welfare, is not married, and has no male authority figure to assist her. It is clear that Dorothy, Jasmine, and Wendy were all waiting to have children under more socially desirable conditions; with a husband. It is also seen with Zoe as she tried to conceive while she was engaged to her fiancée. Unfortunately, for Black women who have fibroids that affect their ability to get pregnant, wanting to uphold social mores presents another obstacle and further complicates the option of motherhood among these women.

Weighing treatment options with hopes of motherhood and being symptom free, was also a struggle for Chandra who was single with no children. Even though Chandra, age 46, had no plans of having children, she wanted to have the option just in case she changed her mind. She continuously went back and forth about the permanency of being pain free or preserving her ability to have children:

I had reached a point. I really wavered between myomectomy and hysterectomy. I mean really to the point where, one day I wanted a myomectomy, the next day I wanted a hysterectomy. I just needed it to be done, and the idea of no longer having the problem, by having a hysterectomy, was exciting. But not having the ability to have children was depressing. So all those other things are good and I support them, I just had reached a point. I was tired of checking myself and wondering if I feel myself bleeding. Was anybody behind me, can anybody see it, is it covering my clothes. I mean you don't want to live like that, but you just get to the point where you're like, no, this is too much. So myomectomy it was.

Chandra was initially leaning towards having a hysterectomy in order to prevent the fibroids from growing back and having multiple surgeries, but despite that fear, her desire to preserve her fertility “just in case,” was stronger than permanently ending the struggle with fibroids.

In the previous chapter, the stories of Lynn, Lisa, and Leleti depicted the complications of fibroids with childbirth experiences, where all three knew of their fibroids but were pregnant before they could do anything about them. Conversely, Elise and Sophie were able to conceive and have children, but could not do so without some type of medical intervention for their fibroids. Elise's first treatment for her fibroids was in her twenties when she participated in a clinical trial at Georgetown:

The hysterectomy wasn't an option. I hadn't gotten married and had no children yet. So the treatment that was really new at that time, it was at the Georgetown Medical Center. It was the uterine artery embolization, that's what it was called, back then. I think it is now uterine fibroid embolization, and I wanted to try it but I didn't want to have the surgery. It sounds crazy to me now, but I was too nervous to take the time off from my job, and I was the first Black woman at that law firm . . . it seemed like too much tension in my first year there.

It worked successfully, but when it came time for her to conceive after she had gotten married, she could not. She mentioned that the infertility was the most troubling issue for her regarding her experience, but she later had a myomectomy, and was able to get pregnant right away. Elise had other concerns as a consequence of having had thyroid cancer. Prior to having her second child she also had to decide between delaying her radiation treatment and trying to conceive before her fibroids grew back. After researching the pros and cons of delaying radiation treatment, she in fact did delay, got pregnant again, and delivered a healthy second child. Her thyroid treatment resumed after she was born and the cancer has not returned.

Sophie was another participant who had to have a myomectomy before she could get pregnant. As a Black lesbian she had other contentions to deal with in order to conceive without a male partner. The only reason she found out about her fibroids was due to the series of tests she had to do before insemination:

And that's when they said, oh you may have fibroids. Then they said that based on where it is, you're going to need to get that, get it removed; because I had one major one at the top of my uterus that was in the walls, and then I had a couple of other smaller ones. And the one that was at the top was the one that was concerning. They said it was like a 50 percent chance of a miscarriage. I did get a second opinion, because I was like, what, I have to get this removed, I have to have surgery? So before doing that I got a second opinion and the second doctor confirmed that yes, I needed to get it removed because . . . 1) If you're able to get pregnant because of where it is, the chance is down and then 2) Even if you get pregnant the chance of having a miscarriage is like 50 percent higher than it would be in an ordinary patient.

Sophie ended up doing a laparoscopic myomectomy; because of the recovery time, she could go back to work quickly. She made her decision fairly quickly after finding out about the fibroids because of her age and not knowing how long or if insemination would work. Sophie reflected on the importance of making her decision quickly, so that she would be optimally successful the first go around, "I didn't want to go through all of that and then lose the baby or something like that . . . or continue to try and get pregnant given my age and everything [she was 39 at the time]." Sophie's desire for motherhood was contingent upon removing the fibroids and the myomectomy allowed her to preserve her uterus and successfully conceive within a reasonable timeframe.

Fibroids are currently the leading indication for hysterectomy in the United States; Black women are disproportionately impacted by fibroids with more severe symptoms. It is not surprising then that Black women have higher hysterectomy rates than other racial/ethnic groups (Keshavarz et al. 2002). A recommendation for hysterectomy in light of the historical efforts to sterilize Black people in the United States, can be threatening for some women in the treatment of a "relatively benign" condition like fibroids. Preserving one's ability to have children then becomes more salient during a time when treatment options abound and women are able to choose.

The treatment decisions women made as it relates to motherhood were influenced by their desire to be pain free, their age, and their desire to preserve fertility options. These represent the social variables that motivate a particular treatment choice. Women's race class, and gendered identities influenced why some women delayed childbearing, but not necessarily why they chose a particular treatment with regard to preserving their fertility.

#### "IF YOU DON'T HAVE TO CUT ON ME, I DON'T WANT YOU CUTTING ON ME" – PRESERVING THE UTERUS

While bearing children is important for a lot of women, some women did not want to have children, and the decision about how to treat their fibroids was not about preserving the uterus for childbearing purposes. Some women just simply did not want to be cut, did not want to have a hysterectomy and deal with early menopause, or they did not want to deal with whatever side effects there would be from surgery and unknown effects of not having a uterus. The women in this study discussed non-surgical treatment options that allowed them to preserve their uterus and avoid being cut. These options were CAM, waiting and seeing/watching, and medication.

#### *Complementary and Alternative Medicine (CAM).*

Although there is not a lot of scientific literature about the benefits of CAM for treating uterine fibroids as discussed in chapter two, it is something women have expressed interest in as a way to avoid unwanted medications and surgery. Some of the participants in this study were open to the use of CAM methods to treat their fibroids, and incorporated it into their lifestyle, while some were not receptive to CAM for permanent treatment of their fibroids for a variety of reasons.

Women who did try CAM to treat their fibroids often tried things that were based on their conceptualizations about fibroids. These options were largely centered around diet, detoxing, and being mentally/spiritually balanced. Generally, none of the women in the study used CAM as their only method of treatment against fibroids, except for Nia. Nia, at the time of her interview was a big proponent of using CAM to avoid surgery. Newly diagnosed with fibroids about a month before her

interview with me, Nia had been exploring and trying different remedies in addition to prayer: “So I’m thinking like, shoot, I gotta do some stuff like that, you know, try like this natural herb and things like that, pray. I just went . . . that route, instead of the ‘oh hopeless, and nothing’s going to change, and surgery’s the only option.’” She said that she was changing her eating habits and had posted a list of things not to eat on her refrigerator, which included beef, pork, eggs, sugar, alcohol, pastries, and milk (unless organic). In terms of herbs and other remedies she just started taking Esiac T (in pill form), which is revered for inhibiting tumor growth and treating cancer, along with praying. Upon finishing the Esiac T she will try something called NFX:

And then here’s another one, NFX. This young lady gave me this, it’s an herbal form, says, ‘it supports the female reproductive system, it contains herbs that promote health and circulation and soothes inflammation throughout the genitourinary tract, along with herbs that fight infection and relax and tone smooth muscles, especially in the uterus. It provides herbs that help menstrual imbalances and bleeding disorders, which can complicate conception.’ So I haven’t started taking this one, ‘cause I wanted to do one at a time, I didn’t want to do too much, um as well as changing my eating habits.

For Nia, not yet having fully explored all of her options, it was important to not have surgery right away. Nia believed that she got fibroids because of her long period of taking birth control pills, but when she searched in Google for alternative treatment methods, she came across diet modification and herbal remedies and decided that her fibroids could be treated this way.

Unlike Nia, Halle had been diagnosed with fibroids for a while before she tried CAM. Halle decided to try a more holistic approach after not being able to conceive following her hysteroscopic myomectomy. She was excited to tell me about her experience with dherbs.com:

Halle: So there’s this guy called, oh I don’t know how to pronounce his last name... He has a website, it’s called dherbs.com, have you ever heard of it? . . . he has a whole kit online that’s called the fibroid buster and that’s pretty much kind of how I learned a lot about your mantra, your center being, and all of that. Because he teaches that, first of all, we’re not even supposed to eat meat, we’re supposed to have everything that God made for us that’s from the land, from the motherland, and you know all of that. So I learned a lot just through trying this holistic approach and believe it or not it helped tremendously. I did it.

R: You bought the kit?



Halle: I bought the kit. First I did a total cleansing which was I think 2 or 3 weeks and you go on a vegetarian diet and you take these pills everyday and you drink a lot of water. And at night, you drink . . . it's like coal, this black chalk coal, but it's grounded, it's like a powder, you put it in your water and you have to drink it. . . . I want to say the cleansing was for about 3 weeks and then the fibroid buster was about 3 weeks, 2-3 weeks. And believe it or not when I went back to the doctor, he said that my fibroids had shrunk. So, if I would have probably cancelled my surgery and stayed on that diet, and stayed on that fibroid buster, it may have helped me, and prevented me having to go through the surgery. But I had already scheduled it, and I was just over it, you know what I mean. I don't know what made me try it, I just said let me try it and see, but to my surprise it was working.

Halle was satisfied with the results but admitted it was difficult to sustain because she had to essentially become a raw foodist, a lifestyle to which she was not accustomed and could not sustain. Since diet was also something Halle referred to as a reason for developing fibroids, she and other women felt that if they ate healthier, consumed less meat, kept their bodies detoxified, or simply lost weight, that their fibroids would shrink. Diet monitoring and modification thus became a method that was viable and preferred by many respondents who tried CAM to treat their fibroids. Not only was that diet difficult to maintain in terms of will power, Halle commented on the fact that organic and healthy foods are expensive.

Lynn's first pregnancy had several complications because of her fibroids. She had a myomectomy afterwards and then had her second child, but her fibroids returned again. Although she did not want any more children, she did not want a hysterectomy or surgery, so she tried acupuncture:

I started going to an acupuncturist. And I'm telling you [I don't know] whether it was my mind or my change in habit; 'cause I was taking DHEA tablets, I was doing more magnesium, zinc, and calcium because all of those work together well. I was doing acidophilus because I was having you know with the fibroids, I have issues with yeast and BV all the time. So I was doing those things, and then he gave me some roots [and Chinese herbs].

She spoke highly of the results, and was able to avoid surgery for sometime, but after about a year and a new house, she was no longer able to afford the therapy; the symptoms came back and she subsequently had an UFE. CAM can be a viable option for fibroids as evidenced through the success

stories of Halle and Lynn, however there are class restrictions as well. Lynn was able to sustain a monthly trip to the acupuncturist in addition to the cost of the herbal treatments, but unfortunately it was not financially sustainable for her and her husband even though results were optimal.

Eartha, who is currently trying really hard not to have any surgery and shrink her fibroids naturally, has begun to try some CAM treatments and has plans to make some lifestyle changes: “I’m really not trying to go through all that if I don’t have to. If you don’t have to cut on me, I don’t want you cutting on me.” Through online research, Eartha discovered other CAM options that were more affordable, which included drinking apple cider vinegar, black strap molasses, and baking soda mixed in warm water. She learned that people drank the concoction like a tea and that it did not necessarily help shrink the fibroids, as did those methods described by Lynn, Halle, and Nia, but that it helped with the symptoms, especially the heavy bleeding:

And oddly enough I tried it on a whim. . . . I didn’t have a heavy cycle that month. But it shocked the [inaudible] out of me, ‘cause like the first day was kind of normal, it was kind of heavy or I should say leading up to the first day was kind of heavy . . . [I] happen to be in my kitchen one day and I’m like oh, I have some apple cider vinegar left and I have some molasses; I said well let me just take a shot. Well, I mix up the little stuff, drank it, you know drank some water behind it. Didn’t think too much else of it. Didn’t really realize until probably about 4 days later. I was like okay, this is different. That’s when it hit me, I was like this hasn’t been anywhere near as heavy as it normally would be. I said okay, we might be on to something here, we’ll see. See if this can work 2 months in a row. I’m going to try it.

Eartha intends to look into other natural remedies like Nattokinase (a strong enzyme) which is supposed to attack fibrin (a fibrous protein involved in the clotting of blood) and fibroids, liver cleansing to help get rid of excess estrogen, and she will also go back to exercising and re-establishing a vegan or vegetarian diet within the next month to avoid surgical treatment for fibroids.

Body cleansing is also something that Jill tried to alleviate her symptoms without surgery. She has tried garlic tablets, chickweed, and detoxing her liver. Of both she explained,

Jill: I think it’s like a cleanser or something like that. It’s supposed to shrink fibroids. You put it [it comes in drop form] in tea, or in your food or whatever, because I think . . . the line of the family that it comes from is dandelions or something like that. So it’s

supposed to kind of purify your blood of toxins and stuff like that. It was making me feel kind of queasy, and that's what they said some of the side effects were, so I kind of stopped taking it for a while. So chickweed, also I've been doing liver detox, so I take liver tablets.

R: And why the liver tablets?

Jill: Because basically I'm just looking at the websites that she gave me. But the website that I've been directed to talks about toxins in the liver and the buildup of toxins, so when you flush your liver, it's supposed to help with decreasing fibroids because they think that fibroids has to do with toxins and stuff. So I've been doing liver.

Jill believed that diet and certain foods contributed to fibroid growth; a logical step in combatting fibroids was through cleansing the body as opposed to surgery. In her case, Jill used detoxing as a way to shrink the fibroids, whereas Beverly used detoxing to help alleviate pain and excess bleeding: "I used to eat a box of spinach every day, like after the enemas, and I would drink juice, and that would flush the system out. And that helped a lot. I think a clean colon helped more than anything with the fibroid." Beverly also stopped eating red meat, drank herbal teas like willow bark and milk thistle, but nothing was as effective as the enema. Women's conceptualizations about how fibroids develop were associated with the types of CAM treatments they chose. Both Beverly and Jill expressed how as a result of their beliefs about how fibroids being a build up of toxins, that detoxifying their bodies would help shrink the fibroids and mediate some of their symptoms.

Women who did not seek CAM for fibroid treatment avoided it for a variety of reasons including lack of evidence-based research, lack of time, and having fibroids or symptoms beyond what they believed CAM could fix. Dorothy who is actively treating her fibroids medically and trying to get pregnant described CAM as more preventative and unable to help her: "At that point nothing to me in my mind was going to shrink the size of this thing in any rate or time that I needed it to be shrunk. . . . I haven't really found anything preventative as to why it keeps reoccurring as fast and as big. You're shooting in the dark with the homeopathic remedies I think." Recall from the previous section that Dorothy is trying to conceive rather late in life at the age of 40. So for her, time was of the essence and CAM was something she believed would take more time to work than she had available.

Similarly, Sophie was trying to conceive at the age of 39. Sophie talked about the lack of time on her side to wait for the benefits of CAM to pay off: “If I had more time, yes. But given where I was in my life, I mean I was 39 trying to get pregnant. I was just like, I need to like . . . time is of the essence. I was actually frustrated that I had to go through the myomectomy before I could start. If I was like 35, then yeah.” While CAM may have been a viable option for Sophie years ago, she did not feel she had the luxury of the time it takes for CAM to work and to try and conceive at an optimal age. Given that she and her female partner were not starting their family in the conventional way, there were potential added time barriers to conception by using insemination methods.

CAM was also not a solution for women who had reached their threshold of coping with fibroids, and wanted more rapid improvements than could be offered through CAM. Chandra did not dispute the use of CAM, but for her it was too late to try: “If there was some knowledge given to me at that time, then maybe holistic treatment [would have worked], to prevent what has happened now.” Lack of knowledge when she was first diagnosed with fibroids prevented Chandra from trying CAM. Relatedly, Debbi believed that CAM would have worked, but she had reached a point where her fibroids were unbearable:

Well at the time, because I wasn't as aware of my body as I should have been. I had not [considered CAM], if I had started at an earlier stage, it probably would have worked. But because I was so far gone with it, I wasn't really willing to hold out on anything that wasn't immediate 'cause that was just an uncomfortable point to be in. I wasn't willing to wait.

CAM is seen as a viable option for some women, but it requires adequate knowledge about what can be addressed and how long it will take certain treatments to work.

In discussing her conceptualizations about where fibroids come from, recall how Taraji described fibroids: “fibroids are a manifestation of all your frustration, your pain, your depression, your denial, your aggravation, and lots of the time, shame.” When asked about her use of alternative treatment methods before her two myomectomies, she replied:

The first time I didn't think I was that savvy. This last time my partner was so freaked out, and because it got to such a place, that I knew surgery was needed. . . . that I just didn't [try CAM], other than lots of prayer, lots of chanting, lots of like quiet time. And when I was recovering I did invest in a great deal of post op spiritual care, but not before.

Based on her conceptualizations about why fibroids exist, Taraji used some aspects of CAM as a way to prevent fibroids from reoccurring after her operation. For her however, she felt that it was too late to apply the methods of spiritual care prior to her surgery because the fibroids had already gotten out of control.

Another reason women did not try CAM for their fibroids was because they were skeptical of its benefits and often its lack of evidence-based support of effectiveness. Phylicia was willing to try holistic or herbal treatments but decided not to because there was no proof:

Because I haven't found out any information about that, and what really really works. And I've even asked the doctors, and they don't want to talk about the holistic stuff. They don't want to talk about herbal remedies, the other things that are possibly available for us to take, but we don't know. We don't have the knowledge. And of course, most insurance companies will not cover holistic doctors. United Healthcare does, but Kaiser does not. So when I asked if there was anything else that I could do, like for my anemia . . . [she decided] oh well the iron pills are fine.

Unlike Debbi, Chandra, Sophie, and Dorothy who would have tried CAM if they knew about it in time, Phylicia's skepticism stems from not having enough information about the actual benefits of CAM. There is a level of trust that Phylicia has for medical professionals and the scientific process. Her skepticism is built on the lack of endorsement from her own doctors and science in general.

Lena's skepticism was centered around her experiences of rapid fibroid growth, faith in the medical profession, and the perceived risk associated with using CAM. Lena reflected on why she was unwilling to try CAM:

Lena: Probably scared, didn't want to risk it. Once I realized . . . how fast it was growing and stuff, I think the urgency . . . even talking with my ex-husband, there was more a sense of, 'you can't take those chances.' I could, but it's like you're going to be more damaged if I did, so I kind of stuck with the medicines.

R: Because you felt that holistic treatments would take longer or...?

Lena: Not necessarily longer, but . . . I've seen the good and bad. I've seen people who it really worked for, and I've seen people who tried and unfortunately it didn't; and they couldn't undo the damage that was already done. I think that that was my fear. If I did too much damage, you couldn't undo it. . . . I think I let fear drive that more than anything. Not that I don't trust it, but I let fear drive it. Because I've done holistic for other things, like my migraine treatments, and if you drink this and don't do this. . . . You don't need this pill, just take this.

For Lena it was a risk to try something that might not work, or cause more harm than good and she didn't feel like she could take those chances. She was influenced by her husband to avoid CAM because of his background knowledge in the medical field and trust in the medical model. As seen with Lena and Phylcia more trust is placed with medical doctors, which instills fear and skepticism for the use of CAM to treat fibroids.

One's professional environment can also contribute to skepticism of CAM use, as was the case with Lisa. Lisa works for a government health agency and is well versed in scientific research claims and evidenced-based research. She at first was not sure why she did not use CAM and then later thought about it in the context of her work: "But I don't know why I don't do it, being in this type of environment, if it's not evidence-based, practice-based, educated, regulated [it does not work]. So if they're not saying that it works, it probably doesn't, so maybe there's the skepticism." Lisa recognized that her belief about the non-effectiveness of CAM is because it is not tested and proven, or regulated. Had she worked in a different occupation, she may have had a different opinion about CAM.

Lastly, a couple of women, Leleti and Robin, indicated that they did not try CAM for their fibroids, but engaged in what I would consider to be CAM methods with regard to their treatment of symptoms. When asked why she did not consider CAM as a treatment option for her fibroids Robin said, "generally, if it's not mainstream, been tested and approved, I usually don't go there. I'm not opposed to it, but I would just like to have more research on it, just to feel comforted that it's going to be ok." Robin indicated during her interview that her treatment choice for now was to "wait and see," however she also mentioned finding that her healthier eating and increased exercising helped with her symptoms

throughout her “wait and see” process. These were activities she has actively been engaging in since her fibroid diagnosis.

When asked about using CAM for her fibroids, Leleti retorted, “I don’t think so, sorry. I don’t have much confidence in that (laugh).” Her response had a lot to do with her background as a veterinarian and from growing up and living in Nigeria:

Background matters a lot with me because when you talk of herbs in Nigeria . . . I know with my medical background, I know that medicine came from herbs, but you can quantify it and know the actual dosage you’re taking. But back home in Nigeria, all those herbs you do . . . if somebody does consult with a conclusion and tells you that it has been working and so on, there is no documentation of all its effects and side effects and so on. And also, some mix spiritual with it, that aspect is the major aspect that I have not been able to want to try it. I don’t want to mix or dabble my hands into something that I will not be able to get my hands out of . . . when I’m praying and it’s like I’ve dabbled into it. But I’ve heard there are some herbs here [in the United States], I’ve heard about those ones, and I know at least that FDA [Food and Drug Administration] will not approve anything that has not been tried and satisfied. But with my background thinking of, and belief about herbs, I’m not motivated to do that, or try it, even knowing that it’s different from what is back there [in Nigeria]. But that has already affected my thinking and so on.

Holistic healing options are different in Nigeria than how they are understood in the United States. In Nigeria, the voodoo like practices accompanied with herbal remedies appear to represent an incorporation of spirituality, it is not the same as her Christian faith and not something that she wants to mix together. With that said, Leleti did share that her first treatment of choice was to go with faith and leave her fibroids in the hands of God. She proceeded to tell a very serendipitous story:

That was when the man gave us the treatment options of: this medication . . . hysterectomy, or there’s a fourth one I’m missing that I can’t remember. So when I saw him and they gave me those options, I was like okay fine. He [husband] was not around at that time. So naturally, I had to go and discuss with my husband and they said okay. So when I came, I discussed with him (laugh) and he mentioned okay, fine, those four options are from man, but we have a 5th treatment that we’re going to follow and I was like, what is the 5th one? He said, faith (laugh), and I was like, oh my God! (laugh) I’m a Christian, we practice religion and counsel people, and counsel faith, and tell people they have to have faith and so on, and my husband is telling me I have to practice faith. And I said, are you crazy? This is a medical problem, so anyway, that’s what we associate, and he now followed me to the doctor the next time and he told the doctor, thanks for these suggestions you have given us, we’re going with faith, we’re not doing any of those, and we believe that God is going to take care of this. And the doctor is also

Christian and he said okay, I agree with you and draw my case with you. That is it. And I went through that for the next 9 – 12 months and at one time I noticed that the bleeding reduced. And I was like, it is our custom . . . with the pastor we had been sharing and praying and start really trusting God. So in a nutshell, it seemed that the prayer was working, that I'm seeing less of bleeding and so on that work would be happening so he doesn't know that we had been asking God and everything. So the next time I saw him, he said that, he might be wrong but he received that God is saying that I'm pregnant, I was like how can I be pregnant, I see blood.

Sure enough Leleti was pregnant, and her experience was shared in chapter five, where she released a lot of clots and lost a lot of blood in the delivery room after her baby girl was born. She believed it was the fibroids coming out, and after "about 6 months or 9 months after the delivery I went for ultra sound, and when I went, the question the doctor asked me was, did I have fibroid before? I said, well as far as I believe, God has taken care of it, I just . . . I said why did you ask me that, he said he could see some scarified patches in my uterus." She was able to confirm what she had suspected through her follow-up visit, that God had taken care of her fibroids. Leleti did not want to have surgery and up until a few months before her interview with me, the only treatment method she had used was faith and prayer. However, she was in the process of pursuing other medical interventions because her symptoms were returning and progressively getting worse.

Faith is an important consideration with regards to being a widely used type of CAM, particularly for Black American women. In a study of CAM use among women in the United States, Upchurch and colleagues (2007) found that Black and Hispanic women more likely to use prayer for health than other methods of CAM. "Prayer for health" was defined as, praying for one's own health, having others pray for their health, participating in prayer group or prayer chain, and/or a healing ritual or sacrament for one's own health (Upchurch et al. 2007). While the study was conducted with women in the U.S., Leleti's course of actions would fall under the "prayer for health" category.

#### *Wait and See*

Women who were close to menopause, were not symptomatic, or who had tried other unsuccessful treatment methods entered into a "wait and see" period. Here they were essentially



waiting to see if their fibroids would cause any major problems that would require medical intervention, or biding time while deciding on a treatment. Robin and Jill mentioned above, seem to be managing their symptoms satisfactorily without birth control, or the need for surgery or other procedures. They find this method is the best option for them since they are not actively trying to conceive. However, Jasmine, Leleti, and Nia are all in a state of “wait and see” despite experiencing very bothersome symptoms.

Waiting and seeing is often combined with other treatments and dependent upon how long ago they were diagnosed or became symptomatic. For example, while Jasmine has had a D&C, and still has her IUD, she does not intend to have surgery until she is ready to try and conceive, so she is waiting. Nia, who is newly diagnosed is just beginning to explore her options and will continue to pursue holistic treatments while she is waiting and researching all of her options. Additionally, fibroids tend to shrink after menopause, and Dihann, Della, Pam, and Nell, decided against recommended surgeries and opted to wait it out until they complete menopause in hopes that their fibroids will shrink.

As an option to avoid surgery, hysterectomy, and buy time, waiting and seeing allowed the respondents to determine the best treatment course for themselves. For some women, not taking any action is an act of resistance against doctor’s recommendations, which will be further discussed in chapter six, and the resistance is sometimes due to a lack of trust in their doctor for treating their fibroids. Past experiences with doctors, and continued experiences with unsatisfactory treatment also predispose a woman to wait and see if her symptoms progress or dissipate.

### *Medication*

A number of respondents (N=7) were prescribed birth control pills by their doctors to regulate their cycles, decrease the bleeding, and minimize the pain caused from fibroids. However, because of their conceptualizations about birth control and past experiences, there were only a few women in the study who used birth control as part of their treatment regime for fibroids. Lynn expressed how her

previous experience with contraceptive pills influenced her decision to not treat her fibroids with birth control and discussed her thoughts about having increased estrogen in her body: “I don’t want to take a hormone, I’ve been on birth control pills maybe once in my life and it made me nuts. And it’s obvious that extra estrogen on top of what I already have is not good for me, hence the pregnancies you know.” Lynn agrees with the medical literature that fibroids result from increased estrogen in the body, and did not see the point in taking a medication that increased estrogen in her body as a way to control fibroids.

Wendy, Jasmine, and Lena’s experiences with birth control are discussed in previous sections as they related to weighing their fertility and fibroid treatment. They all used birth control as part of their treatment regime to manage pain and other symptoms, along with Elise and Beverly. Elise explained, “I’m trying to manage my cycle on birth control pills and not have one because I don’t need it. And my gynecologist said it just hasn’t been working, the fibroids are very harmful . . . if I can get the right birth control pill I wouldn’t even have a period at all. And that’s where I’m trying to get.” Although she is not taking birth control pills now to manage her fibroids at age 62, Beverly used birth control when she was younger and said that the pills did help.

When birth control pills did not work, or was not conducive to her memory (remembering to take the pills), Nell switched to an IUD to regulate her cycle and alleviate some of her fibroid symptoms. She described her unpleasant experience with her IUD:

I had the IUD once and I bled for almost 30 days. And I was like, take this damn thing out! Take it out! But the doctor was like, you know that thing cost \$500? I was like I don’t care if it cost \$5 million, I have bled for 30 days! But don’t you want to take some pills. No, that’s why I got the IUD so I didn’t have to take no pills, right? So I took that out. But it worked well when it worked. I had it for a year, but after a year I was like no, take it out, ‘cause I was bleeding too much.

After the IUD was taken out her doctor prescribed Lysteda, a fairly new non-hormonal drug that decreases the amount of blood flow during a menstrual cycle, and is only taken during the menstrual cycle. She was excited about this pill, because although she does not like taking pills, she loves this one: “So you take it 3x a day for 5 days when you’re bleeding and it decreases the amount of bleeding you

do. So now I don't bleed that heavy and I don't bleed as long." Lysteda had changed Nell's life, and it was evident in how she lit up when talking about the benefits at different points throughout the interview. Although she was averse to taking medication, Lysteda allowed her to avoid unwanted surgery while she waited for menopause, and alleviated her most bothersome and disruptive symptom.

Pam was also prescribed a medicine to stop her heavy bleeding and pain: "it stopped the bleeding, stopped the cramping, but it shot my blood-pressure through the roof. I can't think of the medication name right now. It's supposed to restrict your blood vessels, and so that's what stopped the bleeding. And if you have fibroids, it causes some to shrink . . ." Although the medication did alleviate her symptoms, she could not risk having constant high blood pressure.

Pain medications were also prescribed and utilized by women to manage their fibroids. Several women just managed pain by doubling up on over the counter ibuprofen, Motrin, Advil, and/or Aleve, or taking prescribed 800-milligram ibuprofen. However, Zoe and Lena talked about the need for something stronger, and explained how they took prescribed Vicodin or Percocet for their pain. Zoe reflected on this type of treatment she is currently under while she waits for her pending partial hysterectomy:

I have developed, I wouldn't say a dependency, but in order for me to control the pain, I have to take Vicodin. . . . it's medically prescribed, so I'm not buying something off the street. But that's how my doctor is treating me to control the pain, and I really don't like to take the Vicodin so much because that causes other side effects.

Zoe is apprehensive about saying she has become dependent on pain medication, but she acknowledges that she must take it in order to function. Having to take a drug as strong as Vicodin illustrates the magnitude of pain that some women suffer from fibroids.

Lena also spoke of the necessity of pain management in order to function when she was struggling with extreme pain:

I had actually gotten to the point that I had Vicodin and Percocet. There was even one point where I had morphine. So that's how painful they got for me, where I could take those and still function. So it was more like a pain management because the pain was so intense.

Currently Lena is on a birth control dosage that does not allow her to have a period, hence freeing her of

the intense pain that required taking Vicodin and Percocet. She was able to exchange one form of medication for another to control the impact of her fibroids. Without medication, some women like Nell, Zoe, and Lena, would not be able to function at all.

The type of treatment women chose was dependent upon the impact it had on their lives, and their beliefs about how fibroids develop. Some women in this study prefer not to have surgery because they feel there are other non-invasive methods available to them through CAM, waiting and seeing, and medication. It is important to consider these surgery alternatives in an era where Black women are more likely to have hysterectomies as a result of fibroids; a surgery most women did not want to have.

#### “I GOTTA GET THESE THINGS OUTTA ME” – THE INVOLUNTARY VOLUNTARY HYSTERECTOMY

Uterine fibroids are the leading indication for hysterectomy in the United States, and Black women are more likely to have hysterectomies due to the increased likelihood of having fibroids (Whiteman et al. 2008; Bower et al. 2009). In this study, there were 10 women who chose the permanent “cure” for fibroids, a hysterectomy or partial hysterectomy. Participants came to this decision either as a last resort after having tried other treatments, or they were simply ready for a permanent resolution. The hysterectomy experiences of Josephine, Zoe, and Wendy were discussed above as they related to motherhood, however six other respondents also had hysterectomies.

##### *The Last Resort*

Prior to having their hysterectomies, several women underwent other treatments for their fibroids. The prior treatments did alleviate some of the symptoms for a period of time, but as is the recurring nature of fibroids, they grow back and symptoms do return. Ruby’s initial resistance to the hysterectomy was less about wanting to preserve her ability to have children and more about her desire to avoid the pain of surgery. Motherhood was not a factor in her treatment decision, which was first an UFE and followed by a partial hysterectomy. When asked about having children, she said: “It’s never been something that I wanted. Never thought about adopting, never wanted to have children.

Remember . . . the pain thing? Yeah, never wanted to be pregnant.” The “pain thing” Ruby refers to is associated with her desire to avoid surgery because she does not like pain: “The idea of anybody cutting me didn’t sit well with me. I have an aversion to pain and an aversion to hospitals. And I just didn’t want to do that if I didn’t have to. Last resort.” Having a partial hysterectomy was absolutely her last choice. Despite her anxiety over pain, which was very strong, she still went ahead with the surgery because the symptoms had gotten worse and she could no longer manage.

Getting a hysterectomy was the last thing Cicely wanted, but she had no choice. Cicely suffered from embarrassing, spontaneous, extremely heavy bleeding episodes. She didn’t want to have surgery initially, so she opted for a laser surgery to provide some comfort and relief from her fibroids:

I believe they told me that they could actually try to go into the uterus and try to remove them there. But for some reason I didn’t want them to do that. I just wanted them to take care of the ones on the outside . . . Because by doing the outside [with the laser surgery], it wouldn’t put me down or nothing. I could still function and go to work. . . . then I could see how that worked, and if that helped me I wouldn’t have to go for a major [surgery].

The laser surgery she described burned the fibroids that were sitting outside of her uterus. It worked for about 10 or 15 years and then the symptoms came back worse. She was hospitalized a few times because of her low blood count. Just before the hysterectomy she was hospitalized and had to stay until her blood count rose high enough for her to endure surgery. She was happy she no longer had to deal with the fibroids: “I’m happy that I had a life again, that I could get up and go and plan things and stuff like that, because before I couldn’t.” Because Cicely did not want to have surgery at all, choosing hysterectomy was the last resort. Literally for her, she had to have one or bleed to death, despite her opposition to major surgery.

#### *Ready for Resolution*

Aside from Josephine, only two other women in the study had hysterectomies without trying other treatment options first. Both had reached a point of no longer wanting to deal with the fibroids and wanted a permanent resolution. Whitney, aged 35 at the time of the interview, had no desire to

carry a child and did not see the point in continuing to endure her symptoms of heavy bleeding and protruding stomach:

I mean I had fibroids that were over 30 cm. I was like 9 months pregnant, my fibroids were that big! It was disgusting. And also, based on the fact that I didn't want to give birth for children, it didn't bother me to have a hysterectomy at all. I wasn't worried about that. Now I'm dealing with hot flashes. They're not as bad anymore, but I'm dealing with just that. That's pretty much it. But I think it was the best choice I ever made for me. It's not for everybody.

What ultimately led her to a hysterectomy was her enlarged uterus, which made her think, "No, I gotta get these things out of me." To avoid known risks associated with hysterectomy, such as cancer, Whitney opted for the laparoscopic partial hysterectomy to preserve her ovaries, so that she could use her eggs in the future with a surrogate. Overall she was satisfied with her decision to have the less invasive procedure and to be symptom free, with a flat stomach.

Alfre had a full hysterectomy in her early 50's and was completely ready for it: "Fortunately since I was past childbearing years and stuff, you know losing the uterus wasn't that traumatic." She wanted to pursue other options but they did not guarantee the results that she was seeking:

I looked into the embolization. I would have had to go to a different doctor, different facility. I think there was one Kaiser facility in another area that had some doctor that did embolization. But as I read about it, they were talking about the size – if they were a certain size then they wouldn't shrink down that fast, or they would only shrink to half that size. So . . . if it's the size of a grapefruit and half of that [will shrink], I'm still gonna be full of fibroids, you know. So even though that would have been probably better than the surgery, because I don't really like to do the surgery and all that, I didn't think that was going to solve the problem with the fibroids.

In the end she was satisfied with her decision, but not necessarily ready for the effects of menopause, "it's much better except for the fact that now, I have all these symptoms of menopause. So I have all the hot flashes and all that. So that part I don't like. But as far as the fibroids and the uterus, that feels a lot better." A permanent solution was important for Alfre and hysterectomy is the only treatment option that can provide such assurance. After weighing the pros and cons of other options, she was ready for a resolution.

## CONCLUSION

Treatment decisions for uterine fibroids among participants in this study were focused on three major factors – preserving fertility, discomfort with surgery, and the desire to find a permanent solution. Some women experienced a struggle between choosing a method that would both alleviate symptoms but preserve their ability to conceive. This decision making process affected women who were not yet ready to start a family and did not know what would be the exact impact of fibroids on their fertility, or ability to carry a child. Even for women who had children, or had passed their childbearing years, there remained a strong desire to preserve their uterus or avoid surgery and hysterectomy, if possible. Finally, for those that did have a hysterectomy, it was either a last resort or they were seeking a permanent solution.

As the title of this dissertation suggests, some women found fibroids, which were literally the size of grapefruits in their uteri, to be unbearable. For Black women considering motherhood, treatment decisions are particularly important given Black women's higher rates of infant mortality, low birth-weight infants, and hysterectomies (Keshavarz et al. 2002; Matthews and MacDorman 2013). While historically, Black women experienced discrimination and abuse in healthcare settings, their experiences are different in the twenty-first century. Black women have more access to care and have a variety of options for medical treatment. Some options were financially restrictive, particularly CAM methods (vegan diets, herbal medicines, acupuncture) and surgery, but the treatment decisions for fibroids not necessarily influenced by their race, class, gendered, and class identities. Women were more about preserving fertility, avoiding surgery, and wanting a permanent solution; the other social variables that Brown (1995) implicated as influencers of treatment decisions. Race, class, and gendered identities did however influence *how* women made their decisions, to be discussed at length in the following chapter.

## CHAPTER 7: PATIENT AGENCY AND BLACK FEMINISM

### INTRODUCTION

In 1972, Reeder discussed the implications of changes in the structure of medical care on the role of patients in health care settings. Reeder (1972) identified three structural changes: the shift in medical care from treatment to prevention, the provision of medical services within bureaucratic structures as opposed to private practices coupled with the “growing sophistication with bureaucracy,” and the growth of the consumerism social movement. The rise in patient consumerism and autonomy during the late 1960’s was followed by a steady decline of public trust in physicians (Reeder 1972, Lipset and Scheneider 1982; Pescosolido, Tuch, and Martin 2001; Timmermans and Oh 2010). It was the erosion of trust in the late twentieth century that accelerated patient consumerism in the form of patient health-seeking behaviors which included patient self-care, self-diagnoses, engaging in online self-help communities that empower patients interactions with their doctors, and the increase in use of CAM (Freidson 1970a; Reeder 1972; Timmermans and Oh 2010). The shift from a paternalistic patient-physician relationship towards one rooted in consumerism allows patients to take on a more proactive role in the medial-decision making process (Lutfey 2005; Charles, Gafni, and Whelan 1999) thus giving patients more autonomy in clinical encounters. Black women in this study had a lot of autonomy with regard to how they managed their fibroids. They exhibited patient agency in ways that were influenced by their race, class, and gendered identities. This chapter will first provide an overview of patient agency and how this process is unique for Black women.

#### *Patient Agency*

Previous sociological research has explored the autonomy of patients in the clinical encounter using varying terminology, including but not limited to, “patient autonomy,” “expert patient,” “patient empowerment,” “the activated patient,” and “patient agency.” Previous research on this concept of autonomy among patients explored the doctor-patient interaction in observational studies and whether



or not patients resisted or accepted doctor recommendations (Koenig 2011; Costello and Roberts 2001). An “empowered patient” is one who is highly interactive, communicative with health care providers, in instances of inadequate treatment the empowered patient will end the relationship with that particular doctor (Hayes-Bautista 1976; Marelich et al. 2002). Reeves and Arnold (2006) found that patient empowerment among patients with HIV/AIDS affects the traditional medical relationship through patients’ assumption of responsibility for their health care decisions, the redefinition of patients’ perceptions and expectations of their physicians, and the promotion of a partnership approach to health care (Reeves and Arnold 2006).

An ‘activated’ patient has been described as a patient who:

rejects the passivity of sick role behavior and assumes responsibility for their own care. They ask questions, seek explanations, state preferences, offer opinions, and expect to be heard. As a consequence, active patients are more knowledgeable about, satisfied with, and committed to their treatment regimens. (Steele et al. 1987: 4)

A patient who exerts patient agency is also rejecting the passive sick role. Costello and Roberts claim that patient agency occurs at the individual level and is both apparent and operative in that “physician power does not unilaterally determine outcomes. Patients are active in negotiating treatment plans through their acceptance of or resistance to recommendations – thus embodying agency in the medical setting” (Costello and Roberts 2001:243). Patient agency has been researched in the context of patients having the ability to choose a particular path of treatment, comply or not comply with a doctor’s treatment recommendation, find doctors, research health information for themselves, or find support groups online for their particular condition (Lupton 1997; Costello and Roberts 2001; Barker 2008;). Patient agency, then, is the power to manage one’s health through various acts that allow the patient to be actively involved in their health and better informed when interacting with medical professionals.

The terms described above appear to be easily conflated, but all explain the phenomenon of the patient taking some control over their relationships and interactions with doctors. Patients who are empowered, informed, and actively participate in medical decision-making have been shown to have

better health outcomes, more positive doctor-patient interactions, report greater levels of communication with their providers, and receive more information than those who are passive (Greenfield, Kaplan, and Ware 1985; Greenfield et al. 1988; Kaplan et al. 1989; Malerich and Murphy 2003). Having patient agency fosters the development of becoming an informed patient in the clinical setting. Imber (2008) discussed how the informed patient ideal also contributed to the decline of doctor's moral authority over patients.

Despite the varying terminology used to describe a similar phenomenon, patient agency will be used to explain the phenomenon of the empowered, activated, and informed patient for the women in this study because it best represents the recurring theme that was expressed in their narratives: women have, are aware of, and exert their agency in the treatment course for their fibroids. For this study, it was hypothesized that respondents would reject the sick role. This was evident in chapter five with regard to participant's experiences with fibroids, however rejecting the sick role is also relevant in the discussion of how respondents assumed responsibility for their own care through the embodiment of patient agency. Patient agency occurs in a different context for Black Americans, who are leery of the medical profession and who have experienced well-documented racial discrimination in clinical encounters. So, how does patient agency shape Black women's experiences in and outside of the clinical setting, and what are the implications with regards to treating fibroids?

#### *Black Women and Patient Agency*

Upon diagnosis of an illness or condition, doctors have the opportunity to establish a trusting relationship by explaining what fibroids are, how they can be treated, and what to expect from each treatment option available. Additionally, through patient agency, the patient is at liberty to ask questions, explore treatment options, and make decisions on her own behalf. Patient empowerment research on women for other diseases has shown that women receive more information and communication from physicians and report better overall communication with their providers compared

to men (Hall, Roter, and Katz 1988). In their meta-analysis, Hall and colleagues (1988) attributed this gender difference to the fact that women ask for more information, receive more health services, and solicit warmer responses than men; they have greater patient agency and are more empowered. While they did not do any intersectional analysis, they reported that white patients compared to Blacks or Hispanics, and higher social class patients compared to lower class patients, received higher quality care and more positive talk. However, because Black Americans have historically and continue to have unique experiences of discrimination from healthcare professionals based on stereotypes (Kreiger and Sidney 1996; Lillie-Blanton 2000; Bird, Bogart, and Delahanty 2004; Blanchard and Lurie 2004; Burgess et al. 2008) they are less likely to trust medical professionals, which leads to a less than optimal doctor-patient interaction (Blanchard and Lurie 2004; Trevedi and Ayanian 2006; Musa et al. 2009). So then how do Black women navigate this terrain, exerting patient agency and combatting medical mistrust?

The work of LaShaune Johnson, Patricia Hill Collins, and Mary Abrums offer frameworks on patient agency and Black women from which to build. A relatively recent exploration of Black women's patient agency is in the work of LaShaune Johnson as it relates to breast cancer, a health disparity among Black women that is often overshadowed by mainstream breast cancer organizations. She explored the experiences of Black female breast cancer survivors and the leaders of Black female focused organizations devoted to preventing breast cancer and providing resources. It is crucial for Black women to become empowered patients in light of several challenges faced by Black women with breast cancer and the organizations that target prevention and outreach among them. Johnson discussed the political and practical process of becoming a Black empowered female patient:

The creation of the Black empowered female patient is both a political and practical process. It is political because it acknowledges the historical and contemporary forces that influence the lives of Black women—their search for knowledge is as much influenced by wanting to know about breast cancer as it is about seeking information they believe may be withheld from them due to institutional racism. . . . The decision to become a Black empowered patient is a practical one as well. In a state of advanced marginalization, these small, locally run groups are not in a position to make or even demand structural changes in the ways in which resources are distributed and the ways

in which healthcare is practiced. They have to work with what they have— what they have is an imperfect, uneven medical system that occasionally rewards the “squeaky wheel.” If these groups teach women how to be a thorn in the side of biomedicine, perhaps they can impact health disparities, one woman at a time. (Johnson 2009:180)

In light of the necessity to become empowered patients, Patricia Hill Collins argues that Black women engage in multiple strategies to resist oppression and the controlling images placed on them by society. Collins explained how these acts of resistance can be expressed through relationships and interactions with other Black women, art, music, literature, but also through Black women’s consciousness, “the ‘inside’ ideas that allow Black women to cope with and in many cases, transcend the confines of intersecting oppressions” (Collins 2000:98). Some acts of resistance may never be verbalized, or may be expressed in the form of a change in thought; they are acts of resistance nonetheless. Individual acts of resistance represent collective activism against oppression and can be applied to health and the experiences of medical mistrust, mal-treatment, and neglect by the medical profession.

Mary Abrums’ study examines how Black women exert patient agency in the face of discrimination in doctor-patient interactions. In Abrums’ analyses of discrimination in healthcare among poor and working class Black women, she found both active and subtle forms of resistance through her participants’ patient agency (Abrums 2000; 2004). Active forms of resistance took the form of complaints, direct challenges to provider, and refusals to go to the doctor, whereas subtle resistance was found in their religious beliefs and their faith in God to guide doctors who cared for them. Contrary to Abrums’ study, most of the women in this study were middle-class and above, and engaged in both active and subtle forms of resistance to medical authority. Few women in the study expressed feeling discriminated against, or commented on racially gendered assumptions made by their doctors, but there was some evidence of these experiences. In this study of Black women with fibroids, merging theories of patient agency with the work of Collins (2000), Abrums (2000), and Johnson (2009), illuminates a framework through which Black women engage in health activism by becoming advocates for their own health and empowered patients that are influenced by their race-gendered identities.

## “AN ADVOCATE FOR MY OWN HEALTH”: BLACK WOMEN, PATIENT AGENCY, AND FIBROIDS

In this sample of women, patient agency emerged out of a necessity to advocate for themselves in an arena where their values and needs are often ignored. While women might not have explicitly stated that they experienced discrimination or mistrust from doctors, they did report challenges in navigating treatment options for fibroids, and exhibited patient agency in response. Patient agency specifically represents Black women’s efforts and capacity to act on, or exert power over, how their fibroids are medically treated. In my interviews, Black women explained how patient agency facilitated their research on fibroids, undertaken to become better-informed patients during encounters with medical professionals. Patient agency was also exemplified in the conversations they had with doctors about their treatment options and issues related to their fibroids.

### *Health Information-Seeking*

The act of seeking out more information about fibroids through research on the Internet or with peers represents an act of patient agency. Patients who research their health conditions are doing so to become informed patients in the clinical setting, thus they are exerting patient agency. In a recent study of white middle-class pregnant women in the United States, women used the Internet to complement the trust they had already invested in their doctors, not necessarily to replace traditional sources of medical authority (Song et al. 2012). In reference to the use of Internet for health information, Henwood and colleagues (2003) identified three constraints to the emergence of an informed patient identity in a study of mid-life white women from England. Most women trusted their doctors and did not want the responsibility of seeking health information; there was a lack of “information literacy,” the ability to find accurate sources or know where to research information; and they were met with opposition from their doctors (Henwood et al. 2003). While the study was conducted with all white women, and they were from London, it highlights the inherent trust that is given to doctors, which is not something found among Black women in the United States, as previously discussed. This section explores the impact of

patient agency on health information-seeking behaviors and how and why Black women seek information on fibroids.

There were very few women in this study who did not research fibroids after being diagnosed. As they were diagnosed, and either presented with treatment options or not, most women in the study took it upon themselves to search for information on the etiology of fibroids and their available treatment options. While health information-seeking was not a primary focus of the dissertation, it deserves some attention because it is relevant to Black women's patient agency and treatment decisions.

*Research on fibroids.* During the interview women were asked whether or not, and how, they had done research on fibroids after being diagnosed. Only three women did not research fibroids, Della, Josephine, and Sophie. Della, who was 54 at the time of the interview, was diagnosed with fibroids in her late 20's after her third child was born in the 1980's. She did not have any symptoms at the time, and when the doctor told her she had fibroids, she said she did not research them because, "It wasn't bothering me and it was never anything relevant to me or anybody close to me." Della's experience with fibroids insinuates that had symptoms been worse, or more impactful on her life, she may have done more research about fibroids. Her symptoms did not become worse, and she had not thought about doing more research on fibroids until her interview with me.

Josephine, on the other hand was very much impacted by her symptoms from fibroids. She did not consider herself to be well-educated about fibroids, and what she knew of them was based on the descriptions provided by her doctor. Josephine's treatment for fibroids was a hysterectomy at the age of 29. When asked whether or not she had researched fibroids after her diagnosis, and before her hysterectomy, she replied, "no." Her lack of research is related to how she was socialized to view medical care. When I asked her if she tried CAM for her fibroids before her hysterectomy, she explained, "No. No. Because for one thing, in Black communities, you're not told that . . . you know you go to your

family doctor, whoever your doctor is, and you're told this is the problem, this is how we take care of it. And that's the extent of it." For Josephine, listening to what the doctor said was what you were supposed to do when seeking care, so researching outside of what the doctor had told her was not something she was accustomed to doing at that time in her life. At the time of the interview, she still did not necessarily research health concerns on her own, but she no longer does whatever the doctor initially recommends (especially if it's surgical). Instead, Josephine seeks advice from her younger and more internet-savvy sister who researches her symptoms and treatment options prior to seeking medical care.

Sophie did not know she had fibroids until she was trying to conceive in her late 30's, and indicated that she did not do research about them after she was diagnosed. While she did not research fibroids on her own, when her doctor first told her she had fibroids and that they needed to be removed before trying to conceive, she exercised patient agency by getting a second opinion:

Well for me, because I was trying to get pregnant, I did get a second opinion as to whether I did need to get them removed before starting to try to get pregnant. When I did get that opinion, I found a doctor to do the surgery and wanted to try to do something that was as minimally invasive as possible. I ended up doing a laparoscopic myomectomy. I did it fairly quickly after finding out because I was trying to get pregnant and then I had to wait 2-3 months after the surgery in order to heal before I could start the process.

Due to time constraints, Sophie was more interested in solidifying what she knew about fibroids from one doctor, with another doctor's opinion.

Most of the women in the study (N=28) took it upon themselves to search for information on the etiology of fibroids and their available treatment options. They usually researched on the Internet or read through what little information was provided by their doctors at the time of diagnosis. A couple of women mentioned receiving pamphlets about fibroids from their providers, but they were not satisfied with the level of information the materials provided. Some women shared throughout their conversation how their individual research process helped them in their interactions with doctors.

Alfre, who had a hysterectomy, first wanted to do something less invasive and less permanent but her doctor only provided her with the recommendation of hysterectomy. She researched more about fibroids and found that this process helped her feel more comfortable with her treatment decision:

It kind of gave me an understanding of why. And then if I wanted to ask questions to the doctor I could go on to say . . . why can't I do this embolization? And I'm reading about it, and it says they're only going to shrink so much, or they say you can just wait and not have a hysterectomy and the fibroids will shrink down. But if they're big, the thing that bothered me about that though, was okay so what if they still shrink down, if I got ten pounds of fibroids (laugh) and they shrink to half of that, it's still . . . am I going to still feel those little shrunken lumps (laugh). I don't want to feel that either.

Alfre was essentially saying that because of her research she learned that the embolization process would only shrink her fibroids down by a certain percentage, and she had ascertained that this would not be optimal for her because her fibroids were so big. She initially did more research because she was not given enough information from her doctor to reconcile hysterectomy as her only option. For Alfre and others, having the information is important for Black women who are leery of surgery, so that they are empowered to make the best treatment decision for them, instead of relying on what the doctor may or may not lay out for them.

Zoe talked about how having more information not only makes her an informed patient in the clinical setting, but how having more information about fibroids or other health conditions enhances her patient agency and allows her to be less confrontational with doctors:

It helped me navigate the medical system as far as what to look for and how to identify a good practitioner. It informed me so I was able to have intelligent conversations with doctors and be a more empowered patient, versus just accepting their medical guidance and being able to interact and explore other options before accepting something more final. I relied heavily on the Internet, just reading articles, publications. Whenever I was in a doctor's office, I would pick up any type of literature, and if there were references in that, I would look up those references as well. I'm a researcher by training, so it's just instinctive to constantly look for other answers, and look for other options, and look for other perspectives. But the most important thing I find is that it has empowered me to be able to say yes, I will do that, or no I won't, or I don't appreciate how I've just been treated. So it's made me a more informed patient and an advocate for my own health and hopefully, some of the pushback that I've given doctors has made them better



doctors for other patients. Knowledge as you know is power, and the more I know about the condition the more willing I am to accept medical guidance. Usually if a doctor says something and I haven't read somewhere, and it could be because I just didn't find the right source . . . I'll accept it, but I don't necessarily apply it to my life until I call my cousin and say let's have this conversation.

Zoe calls her cousin because her cousin is a doctor. Zoe goes on to say that that having more information makes her more agreeable and less confrontational and that she is “a lot easier for them to manage” because she is more open to what they have to say. Patients who are more involved and more knowledgeable of healthcare are able to ask questions and be more comfortable with what doctors say; this patient empowerment also requires doctors to provide explanations and information which enables better decision-making (Hardey 1999; Barker 2008; Imber 2008). Zoe's remark about being less confrontational is significant when examined in the context of controlling images of Black women, type-casted as “the angry Black woman” (Collins 2000). Research has shown that when it comes to Black patients, providers are more verbally dominant, less patient-centered in their communication, generally have a less-positive attitude, and show less concern than they show to white patients (Cooper-Patrick et al. 1999; Gerbert et al. 2003; Johnson et al. 2004; Lori, Yi, and Martyn 2011). However, little to no research explores how these interactions differ for Black women specifically.

Lastly, Dihann, who had expressed to me a leeriness of doctors especially after they told her she needed to get a hysterectomy or she would pass out somewhere, explained why researching about fibroids was important to her:

I took the time to look into it for myself, more so than someone saying this is what it's all about, here are your options, and different things like that. So education comes from just – I call myself somewhat defiant – not really, I don't want to say that I don't trust doctors, but I was cautious about accepting their recommendations for how I should proceed when they knew that I had fibroids.

Dihann has a particularly strong sense of patient agency because she refuses to get a hysterectomy knowing that she will soon be in full menopause and off of her breast cancer medication. Both of which, in her opinion and through her research, will shrink her fibroids that are not really bothering her at the

moment. Although her research “wasn’t that deep,” she told me that it was her convictions about doctors that led her to research more about fibroids even though she had already decided she was not going to do anything. Additionally, what sparked her curiosity about researching treatment options for fibroids was the news coverage of Condoleezza Rice having an UFE in 2004. Until that time, she had not heard or seen a lot of information about fibroids, perhaps because information was not tailored or marketed to Black women at that time. In fact, until she mentioned it, I had never heard of a public figure in the news having shared their experience with fibroids with the public. However, given Rice’s role as the first Black female Secretary of State, a high profile position, it is not surprising that her reproductive health status was made public. In this case, for Dihann and maybe other Black women with fibroids during that time, learning about an alternative to a hysterectomy was beneficial.

Previous studies have analyzed how health information-seeking by the patient enhances the doctor-patient interaction, but most were done with white women who are more trusting of the medical profession than Black women. These accounts of patient agency from Black women who feel inclined to research their condition and options, offers a unique perspective through which to view the importance of patient agency. Researching about fibroids provides women with more knowledge that may better equip them in the clinical setting. However, this knowledge may or may not increase medical trust, especially when doctors dismiss the information the women have accessed, or when doctors fail to mention alternative treatment options that the women have researched.

#### BLACK FEMINIST THOUGHT – BLACK WOMEN’S HEALTH ACTIVISM THROUGH PATIENT AGENCY

Black women’s health activism dates back to the 1890’s through the activities of Black sororities, midwives, and public health nurses (Smith 1995; Gill 2010). As time progressed from slavery through the civil rights era and more attention was drawn to healthcare needs of women, a necessary and timely Black women’s health movement emerged in the 1980’s to focus on the health issues affecting Black women (Smith 1995; Gill 2010). Beauticians took an active role by providing community safe zones for

women to share their experiences of trying to live up to unreasonable expectations and how it impacted their health, and becoming health educators in their shops for illnesses such as breast and cervical cancers (Gill 2010). Black female health activist Byllye Avery formed the National Black Women's Health Project (NBWHP) along with other Black women involved in the National Women's Health Network (NWHN) to address the unique needs of Black women (Morgen 2002; Gill 2010).

Through her work, Byllye Avery and her colleagues identified "self-help" groups as a key to addressing Black women's health issues because people in the Black community have always joined together to help one another with everyday problems. The self-help groups developed by Avery and colleagues for Black women were much different than those used in the white women's health movement. In the dominant (white) Women's Health Movement, women were empowered through learning about cervical self-examination as was done in some of their self-help groups, and promoted in guidebooks such as, *Our Bodies, Ourselves*, a book about health written for and by women. Among Black women, however, self-help groups involved discussing feelings, experiences, supporting each other, helping women to make choices based on their own valid experiences and knowledge in the context of being a Black woman (Smith 1995; Morgen 2002; Gill 2010). I liken Avery's self-help ideology to a form of patient agency because of its ability to empower Black women to be more proactive about their health.

This section outlines the strategies employed by Black women as reaction to having fibroids. In this sample of women, patient agency was prevalent in most women due to an inherent necessity to advocate for themselves within the context of a healthcare system that minimalizes health experiences of Black women. Collins (2000) explained that one of the ways in which Black women resist oppression is through relationships and interactions with other Black women (in addition to art, music, and literature). A small number of participants exerted patient agency by relying upon the tradition of communication with other Black women, as it related to fibroids. This form of "self-help" was done in an effort to both

seek and share information with their peers to become better-informed patients in the clinical setting. Women engaged in health activism through *sisters helping sisters* (a self-help ideology similar to that of Avery), conversations with others about fibroids, and acknowledging and addressing the need for more communal conversations about Black women's experiences with fibroids. Health activism also occurred through acts of resistance in the clinical setting.

### *Sisters Helping Sisters*

While Della did not research fibroids after she was diagnosed because they were not bothering her, she decided after having interviewed with me, that I had changed how she viewed her lack of knowledge on fibroids: "Yeah, I'm going to look it up. That's [the interview] changed how I view it. I don't like being too unknowledgeable about things, especially if it's concerning my own health." Not only did her interview with me prompt her to be more proactive about her own health, but the interview also prompted her to talk with her friends about fibroids and other health issues impacting Black women.

I think this has kind of opened me up a little bit. I'm going to go home and Google some stuff. I think we should. I've been planning on trying to do something once a month or every other month with just the females, young and old, to spread the word about anything and everything.

Della's plan to commune with other Black women and talk about life, health, or "anything" is a common tradition among Black women, and is often an empowering experience. Through this act of patient agency on Della's part, she will be engaging in what has been a successful form of health activism for Black women.

The *sisters helping sisters* theme is exemplified through conversations women have with other women about their experiences with fibroids. This process of speaking with other women about their experiences and collecting more personalized pieces of information from women they know, allowed women to understand the options available to them better, especially when interacting with doctors. Debbi explained the importance of talking with other women about fibroids:

Talking with them did help because they were able to give me some information. Because when he told me what it was, I didn't really know what he was talking about. And I'm thinking, God I have these growths in my uterus, what the heck. It was kind of frightening that I had these things that were there and I didn't even know about them growing in my body.

When she did not receive adequate information from her doctor, she engaged in patient agency through conversations with other women. Debbi's patient agency is also expressed through her activism in helping other Black women with fibroids. As a nurse who cares a lot about Black women and their health, Debbi expressed: "a lot of us [Black women] don't have a lot of access to health care, and some of us aren't really aware of our body as we need to be and don't know a lot about what goes on." She continues to offer information about fibroids to other women, and mentioned that it was important for her to participate in this study to help other women as well.

A couple of women discussed how speaking with other women helped them pursue options that they might not have otherwise known about. For example, Dorothy explained, "As soon as I told my best friend, she sent me 2 or 3 people and she's like alright, give [them] a call, she's been through this. She was a great wealth of information, just giving me options." Additional support was provided through these conversations because Dorothy is currently trying to have children. She learned through talking with the other women referred to her that should her treatment options not work, she could prepare for adoption by getting an adoption coach. Responding to the lack of information provided in the clinical setting, Black women found comfort in seeking guidance from women like them.

Nia would not have pursued alternative treatment methods as intently as she did without having had conversations with other Black women from whom she had heard confirming stories. These conversations enhanced her patient agency by encouraging her to research further options for natural fibroid remedies:

I did, I really did [benefit from talking to others]. I talked to [her friend's] friend when she called me, 'cause she had her call me, to encourage me. It really helped. . . . It comforts me, and lets me know that I'm not alone, and I don't have to fear anything, and I think I'm going to be okay. And everybody gave me all their testimonies, their

thoughts on it, people that have fibroids. . . . so all these women around me that have them, they just were telling me what they've heard, and how you can get rid of it doing the natural herbal way. . . . I know one woman that got rid of hers, she did all sorts of things, that Esiac Tea was a part of it, and a lot of other things, like acupuncture.

For Nia, it was important to hear other examples of women that were like her who wanted to try a holistic approach to shrink fibroids. It is evident through the connections that were established for Nia, how powerful sisters helping sisters can be in eliciting patient agency, and the empowerment to try different treatment routes for fibroids. Also, given the racial/gendered nature of medical mistrust and the commercialization of the health care industry, it is significant that the ties between other Black women led to alternative practices in this case.

Eartha discovered natural remedies in much the same way as Nia, by hearing about it from other women and following up with more research, "And it helps to I guess, it helps me to better understand what some other people are doing with it, and it reminds me that I'm not in this by myself. So that always helps and that me looking for natural remedies isn't entirely crazy, 'cause apparently I'm not the only one looking for some." Black women find support from each other and comfort in knowing that they are not alone in their experiences and that wanting to try natural remedies is okay.

Wendy who, did not know that her heavy bleeding and painful cramps were symptoms of fibroids, from initial menses to her thirties, she talked about the importance of sharing with other women what she did not know:

Now people are talking about it [fibroids]. So like for instance, I have a coworker who was telling me that her periods had gotten significantly worse lately and she's like bleeding a lot heavier and all this stuff. And I'm like you might have developed fibroids; you might want to talk to your doctor. Now because people are exchanging and talking about it, maybe she'll go get checked and won't have to be suffering in pain. But because nobody really talked about it other than the fact that you had cramps, it wasn't anything for me to be like, oh well maybe that's something I should check out so I never checked it out.

Wendy's patient agency is demonstrated through her advising women that they may have fibroids based on the symptoms they described to her in a conversation. Other women that Wendy comes into contact

with, who may not necessarily understand that their symptoms may be related to fibroids, will benefit from her health activism. In the act of communing with friends about daily life experiences, Wendy was able to pass on useful information about fibroids.

Taraji shared her fibroid experiences with anyone that cared to listen. She communicates here how important this communal sharing of health information is for Black women:

So most people knew. I'm not private about things like that. I think if you are, you do yourself a disservice, you do your community a disservice, you do the people in your life a disservice. At the end of the day, how would you know to communicate with me about this, ask me, if I hadn't told you?

It is critical for Taraji that she shares her experiences because without it, other women in the community may not benefit from knowing something valuable. She values Black women, and strongly believes in the power of helping one another through sharing of information and experiences.

In the previous section, Alfre explained how researching fibroids treatment options, beyond what her doctor told her, made her feel more comfortable in her hysterectomy decision, but she also shared how she plans to use patient agency to preserve knowledge about fibroids and treatment options to help other women:

But at least ladies talk here and there amongst friends and at work, so you talk about how people have fibroids. At least by doing the research, you can share that information with others, whether you use it or not. So that was probably good, and at least I know about it even though it didn't necessarily benefit me.

For Alfre, while her research may not have benefited her, she recognized the knowledge that she gained in the process could be useful for other women. In fact, Alfre's patient agency extended beyond her interview with me, as she continues to send me things that she thinks might be useful for treating my fibroids.

Nia also saw the value in extending the knowledge she has gained thus far and sharing it with Black women so that they can be prepared:

I feel like if you know it's coming then be proactive. Like for me, I will tell young girls now, that I am learning this about fibroids; wish I had known it sooner. I would say, have

children young because you may get fibroids, which are common in African American women so that it will not hinder, your plans, your dreams, your goals in life, just have children younger. I don't think fibroids are a bad thing; they just prevent you from having children, if they're (laugh) in the wrong place, covering your uterus.

Because motherhood is so important to Nia, who was concerned about her fertility at the time of the interview, she is adamant about helping other Black women who are younger than her. By helping other sisters see how the impact of fibroids on fertility can hinder one's life goals and plans, knowledge that was not passed to Nia, she is able to share other aspects of the fibroid experience that are not found in books, researching, or speaking with doctors.

*A communal void.* A few women in the study expressed concern about the lack of health information sharing among their families, expressing how they wish they would have known so they could have better prepared. Eartha, who is currently suffering from heavy bleeding, and exploring whether or not fibroids will impede her ability to get pregnant, voiced, "My mom was like yeah, that sounds about right 'cause I had them, someone had them, mama had them. I was like well dang, ya'll coulda warned a sister. A little warning would have been nice." Eartha is highlighting the fact that these important issues are not discussed until something happens that *requires* action and/or discussion. The fact that gynecological health information is lost across generations of Black women is evident in Eartha's experience with fibroids. Although I did not always ask participants why these discussions are lacking, Warren-Jeanpiere and colleagues (2010) suggest that the lack of knowledge transferred is due to resisting issues of sexuality and controlling images of Black women as hypersexual. Had Eartha known of her family member's experiences with fibroids, she may have tried preventive measures earlier in life.

Chandra feels that her experiences with fibroids and other women in her family could serve as a catalyst for families to talk about and learn family histories of other diseases. When her doctor asked her if anyone else in her family had fibroids she forgot about her cousin who had them because health issues were not regularly discussed. She explained the effect of not talking about health and the implications of race: "So I think we, just as African American people, we're not very good at



communicating about [health], and talking [about health] and about being vulnerable and transparent. And that's a disservice for us. We hurt from that in many ways." Talking about one's health can put people in a vulnerable position, but it can help save lives when vital information is shared. She went on to discuss how this void in communication can lead to missed screening and prevention opportunities for specific diseases.

Elise also brought up issues of silence in families around health issues when she talked about her experience with her aunts, mother, and cousins not talking about their experiences with fibroids. She wished she would have recognized earlier that her symptoms were not "normal," but actually a result of fibroids. As a twenty-something year old dealing with fibroids, she expressed feeling "a little bit downtrodden" and said her coping would have been better had she known, "Just the mere fact that I would've known that oh, this is apart of my family history that they have these, it wouldn't have been oh my gosh why do I have to deal with this type thing." But Elise also captures the importance of this void of communication at a macro-communal level:

I know that it's not a major public health issue, that it doesn't kill people, but it does impact people, and it impacts people to varying degrees. . . . I just think that it's a travesty that we don't focus more on it in the Black community. Yes, there are other people that are impacted by it, but it's impacting us more than anyone else. I'm not saying we should do a, "do you have fibroids?" campaign, but I just think on a grassroots level, families should be talking about it a lot more. It's not embarrassing. Yes, you're talking about a private part of your body, but that's the end of it. It's not something you got through a sexually transmitted disease, or through living a bad lifestyle. It happens, and you can deal with it. I think that that type of message should be more freely discussed . . . and that type of information should be out there because not every doctor has your long-term life plans in mind. They may suggest something that could solve the problem for now and impact you later, and not everyone has the time or energy to do all the research and find out on their own, and they shouldn't have to. I think it should be more widely discussed. I don't think it's something that we should dump a lot of money into to try to solve and or get rid of. It's not like that, it's just the education needs to be more readily available.

The historical shame and secrecy associated with talking about Black women and gynecological issues is manifested in a silence about issues that impact Black women the most, such as HIV, STD's (Warren-Jeanpiere et al. 2010), and uterine fibroids. Elise encourages families to move past the embarrassment

associated with discussions of “private parts” and create safe and empowering spaces to maintain healthy communities. Johnson’s (2009) argument for empowered Black female patients is relevant here as Elise articulates the challenges Black women face with doctors not having their interests and long-term life plans in mind.

To become informed patients, and feel comfortable with doctor recommendations, and treatment decisions, Black women employ patient agency through their self-motivated research on fibroids and communal sharing of information with other Black women. Some Black women in this study feel that this sharing is lacking. In order for Black women to avoid sojourning through “abnormal normal” symptoms associated with fibroids, and make sure other women know about fibroids and the options available to them, the self-help ideology must persist.

*Patient Agency Through Acts of Resistance in the Clinical Setting*

Health activism also occurred when participants interacted with physicians and medical professionals. One important aspect of the doctor-patient relationship for Black patients is the race and sometimes gender of their doctor. LaVeist and Nuru-Jeter (2002) indicated that the majority of Blacks do not openly express a preference for a Black or race-concordant doctor, and the same was true for women in this study. However, it is important to note that Black patients who are attended by Black physicians have been found to be more satisfied with their medical care and the doctor-patient encounter (Saha et. al 1999; Robins et. al, 2001; LaVeist and Carroll 2002; LaVeist and Nuru-Jeter 2002).

Most women were asked about their race-gender preferences for doctors and the actual race and gender of their doctors, however in some interviews this information was not discussed. Due to the recurring nature of fibroids and the complexities involved in treatment procedures, it would be convoluted to provide an overall number of women who had white male doctors, or who had Black female doctors. Some women had one doctor in 1998 and a different one in 2003, or started seeing one doctor for a myomectomy but later had an UFE with a different doctor. Table 4 illustrates the overall

gynecological preferences for Black women in this study. It is important to understand how patient agency operates with varying doctor-patient concordance. Patient agency intersects with how treatment decisions are chosen, and empowers women to seek out doctors with whom they feel comfortable.

Table 4. Gynecological Preferences

<b>Gynecologist Preference</b>	<b>Participant</b>
Female	Della, Jasmine, Pam, Sophie, Phylcia, Debbi, Wendy
Male	Dana, Halle
Black*	Wendy, Debbi
Non-Black	Lisa
Multiple (non-white)	Jill
Black Female	Dihann, Zoe, Eartha, Patience, Nell, Nia
Either Race or Gender	Elise, Dorothy, Ruby, Whitney, Lena, Loretta, Cicely
Not asked	Josephine, Alfre, Robin, Taraji, Beverley, Leleti

\* Both Wendy and Debbi indicated that they do not have a preference but they both initially look for Black doctors

In the doctor's office, women experienced instances where they felt uncomfortable or did not like the doctor-patient relationship, the recommendations that were given for treatment, or they simply felt dehumanized as if they were just a number or statistic. While the woman may not have explicitly identified these experiences as race, class, or gendered discrimination, there were some clinical encounters that elicited resistance through patient agency and are analyzed here through an intersectional lens. Some women preferred a doctor of a certain race or gender, or race and gender, ultimately, their preferences for doctors came down to how they were treated in the clinical encounter the type of information they were given, the bedside manner in which they engaged, and whether or not they listened to her needs and concerns. Throughout the narratives in this section, the doctor's race and gender are indicated when available to provide a context of the race-concordance or discordance in the interactions being discussed.

Elise's activism was exhibited through her very active engagement in the management of her healthcare. She was aware of offensive behavior in the healthcare setting and responded by getting a different doctor. She saw the doctor's behavior as condescending, and implies that it was most likely

rooted in racially gendered stereotypes of Black people – specifically, that she was an uneducated, uninformed patient who did not know anything about her own health history. After being unable to get pregnant, Elise and her husband sought out a fertility specialist to determine if there was anything wrong. This was about 10 years after her Uterine Artery Embolization (UAE). Here Elise explains how the white male doctor began the appointment:

He started off my appointment drawing the anatomy, on the paper where it covers the table, and explaining how children are born. We felt that he was condescending, and we both have advanced degrees, but most importantly we learned how children were born in seventh grade health, so we were very offended by him. His manner was . . . I mean, he started off by saying things like you're thirty-seven, you're – I was overweight again by then – overweight, you've never been pregnant, you have fibroids, and you had uterine artery embolization. "Maybe you should consider adoption or surrogacy." I was crushed. That was not how I planned for this whole thing to start, so we left there and got a recommendation from a friend for a different place.

While her doctor did not call her stupid or say he would not help them, his actions were insulting and inconsiderate given that he was a fertility specialist who's job was to help them get pregnant. Furthermore, it cannot be ignored that he was a white male doctor. One study among mostly white physicians found that they more likely to view Black patients as less intelligent than whites regardless of age, gender, income and education, and had less affiliative feelings toward Black patients (Van Ryn and Burke 2000). As the encounter continued, the doctor remained adamant that Elise had no chance of becoming pregnant:

He was reading the reports – I had all my reports from Georgetown – "it says right here that the blood flow to your uterus has been cauterized," and I said no, that's absolutely not what it says! I took the paper and showed him that it said catheterized, and that's because after they embolized they went back through and cleared the arteries, the blood flow to my uterus. But he read it wrong, like he just assumed that I wouldn't be able to have children eventually. And believe me, there has been many times when I wanted to spitefully send him beautiful pictures of my children on a monthly basis.

Elise was left in awe by his inappropriate behavior, "he was super condescending, I've never experienced that with a gynecologist before." In reaction to this doctor who was "discouraging and not encouraging," Elise exercised her patient agency and immediately found another doctor who later

determined there was nothing wrong with her fertility, but that she had fibroids again, which needed to be removed in order to get pregnant.

There were other women who sought different doctors based on the way they were treated. It seemed that no matter how Jasmine tried to explain her concerns about her future fertility, her doctor did not understand. Jasmine was completely scared about the risks of taking Lupron injections, which would put her into a state of menopause at the age of 37. First she explained her feelings about this lack of understanding and then what lead her to replace her white female doctor:

I guess people don't understand, when you don't have kids and it's something that you want. And I always thought that I would be a mom. So I don't think she understands how, the only reason I had not agreed to a hysterectomy or something of that sort is because I'm trying to hold on, and I don't think people get it. They just don't get it. . . . So anyway, the Lupron, I was like ok, I'm going to go get a second opinion. So she didn't understand why I didn't want to do the Lupron injections. So her response was just . . . sort of like, well what do you have to lose? That type of . . . and I can't believe that you don't trust what I'm telling you. And I was just like hysterical. Of course I did go and get a second opinion.

Her experience is salient not just because her doctor did not understand her fear, but Jasmine was expected to trust her medical authority and comply. However, Jasmine had lost trust in this particular doctor after having complied with her previous recommendations (IUD) and having negative outcomes. Jasmine resisted by not taking the prescribed Lupron, seeking a second opinion, and switching doctors.

Whitney exercised patient agency when her doctor made an offensive comment about her choice of treatment. The doctor made assumptions about her knowledge of treatment procedures and her ability to pay for them. When asked if her doctor was supportive of her treatment choice she explained:

Once we found out about the robotic surgery, I had said to him, Oh do you perform this surgery? This is what I want to get. And he was like, "well you know it's really expensive." I was like, you know what, I'm not seeing you anymore. I was like why would you even, why would that be the first thing that comes out of your mouth, "it's so expensive." . . . So he was supportive of the surgery but because he didn't know how to do the surgery, he wasn't going to say, oh let that other doctor do it . . . he was trying to tell me, oh it's so expensive, you could do this so much more cheaper even though, from a recovery standpoint it's so different. 'Cause the robotic surgery, it's basically 2 weeks and you're bouncing back. Not even. And also the scarring is very different. You don't even see it, like very small scars, like very little on your body if at all.

Whitney's experience reflects the broader context in which Black women are viewed by medical professionals as not only less knowledgeable but also not worthy of or offered certain technologies that might be available to them. In reaction to this transgression, Whitney's activism came in the form of recusing him from her treatment course. Dorothy Roberts spoke of the racial steering that doctors engage in when they deliberately steer Black patients away from reproductive technologies because of their beliefs about Black women (Roberts 1997). While that may or may not have been the case with Whitney's doctors, it is an important context to consider when examining Whitney's experiences.

Elise and Whitney described verbal offenses from their doctors that elicited an act of resistance. However, Pam responded to a physical incident she experienced with her doctor. She both informed her new white male doctor of his poor technique and decided to choose another doctor:

No. I won't keep him. I won't keep him because he's heavy-handed, he did the biopsy, and that was the third biopsy I had, and I've hurt for almost two weeks after that. It was so painful where the other two times it didn't bother me at all. But then the other two times the other doctor did it, the female. And I told him, just for future reference, when you're doing this for another female, you're very heavy-handed. You need to be mindful of that. I understand you don't have a uterus, so you don't know what that feels like, but you're very heavy-handed. So he was like, oh, well none of my other patients have complaints, and I said that's probably because they did not want to hurt your feelings or say anything to upset you. I said, but I got to tell you before I leave, you're very heavy-handed. And the nurse was there, and I said please remind him. So I would not continue going to him.

The doctor devalued Pam's experience and disregarded her statement because it was not validated by other women's accounts. She exerted patient agency by voicing her discomfort and advising him to be gentler with other women, and was still met with resistance to which she responded with a more subtle but effective form of agency by discontinuing the doctor-patient relationship. Patient agency through active resistance in the clinical setting is important because it gives the woman immediate power to control the doctor-patient relationship, make adjustments if needed, and ensure that she is comfortable with the treatments recommended by her doctor.

In the end, some lessons learned were learned about the importance of slowing down, and listening to their bodies despite everything that is going on around them. Phylicia declared that there was something positive, “because it makes me more health conscious, and more open to new ideas as to what I could do to become even more healthy.” Phylicia is adamant about not getting a hysterectomy and waiting for menopause. She does not know when this will happen but believes that being healthy will be good for her and her fibroids. As a result of having fibroids, she has taken conscious steps to make other aspects of her life healthier.

Debbi’s experience with fibroids also motivated her to be healthier:

Yes it caused me to be more aware of my own body. I focused on everything around me and really focused on me, and so after this experience I’ve become more aware when things are happening with my body. I try to recognize it if it’s out of the ordinary immediately, so I can take care of it before it reaches the point where my fibroids had gotten.

Not wanting to have the experience she had with fibroids, which resulted in hysterectomy, Debbi is taking a more proactive approach to her total body wellness. Fibroids impacted her life both negatively and positively, and she is now a better advocate of her own health.

Drawing on her own research and spirituality, Patience reflected on how fibroids changed the way that she treats her body:

That’s where my relationship with my body, self, and my doctoral work in terms of how I want to affect people, women’s lives positively moving forward. I’m very protective of myself. It’s different. It’s like being in a relationship, that you’re protecting; you know how you protect a child at all costs. So that’s how I’m looking to my body now. Blessing it, nurturing it, loving it, all this nourishing is at a whole other level; in covenant with it [her body].

Having fibroids made her become more protective of herself and changed the dynamics of how she feels about her body. In addition, her experience allowed her to develop another angle from which to study fibroids for her own doctoral research and pastoral care.

Zoe always pushed through the pain, but in her 18 years of experiencing fibroids, she conceded that:

I guess it's forcing me to be more aware of slowing down and taking care of myself. I guess it's also teaching me how to honor myself in pain (laugh) and accept that I'm not superwoman and unfortunately this is how it's occurring. . . . I guess it's a positive consequence. The condition is teaching me that, or showing me that, I can't always push through. Pain is a sign that something needs to be addressed and therefore, I should be more sensitive and allow my body to heal versus just kind of pushing through, and pushing through, and pushing through it. I don't particularly like this lesson, but it seems to be necessary because the more I push through it, it seems like my recoveries are longer and the injuries are becoming more severe. But I just keep pushing through it.

Learning to respect warning signs and not just push through everything was an important lesson for Zoe.

Pain from fibroids literally forced her to slow down, take better care of herself, and reject the strength mandate that so many Black women feel the need to maintain with superwoman-like traits.

As Collins argued, activism is manifested in many ways. For Black women with fibroids, it is found in communal sharing of information and experiences about fibroids. It is also expressed through acts of resistance in the clinical setting by communicating with doctors directly or seeking out more compatible doctors. Finally, throughout their experiences with fibroids and interactions with doctors, Black women have learned that they can be in control of their own health by being more mindful and in touch with their bodies.

## CONCLUSION

This chapter has highlighted the complexities that Black women face in the context of medical mistrust, the controlling images of Black women, and the lack of information from health professionals. In response, Black women with fibroids exert patient agency through health information-seeking to become informed patients in the clinical setting. They receive and share knowledge and experiences with other Black women about fibroids to fill the void of information received from doctors and self-research. In the tradition of Black feminist activism, women also exert patient agency in the clinical setting through seeking different doctors and communicating discomfort. Throughout their exertions of patient agency were the positive implications for self-care, empowerment to manage their health, and the acquired knowledge that they can now share with others about fibroids.



“Whether individual struggles to develop a changed consciousness or the group persistence needed to transform social institutions, actions that bring about changes empower African-American women” (Collins 2000:121). Examining patient agency among Black women with fibroids through an intersectional lens illuminates how race, class, and gendered identities ignite a Black empowered female patient. Patient agency was central to how the doctor-patient relationships were manifested and maintained, as well as influential in how doctor recommendations and treatments were negotiated. Patient agency serves as a tool of empowerment for Black women with fibroids to not only control the course of their treatment, but also to influence how other Black women may pursue treatment for fibroids and the clinical care they might receive. Understanding how middle-class Black women use patient agency to navigate the healthcare system is sociologically relevant given the structural changes in the role of patients that Reeder (1972) identified, and the rise in patient consumerism and autonomy (Timmermans and Oh 2010).

## CHAPTER 8: CONCLUSION AND IMPLICATIONS

From a biological perspective, uterine fibroids are benign tumors in the uterus that can cause menorrhagia, pelvic pain and pressure, abdominal protrusion, back pain, infertility, and adverse pregnancy complications. Sociologically, fibroids have social meanings, influence social relationships, and affect aspects of everyday life. For Black women specifically, experiences with fibroids are influenced by race, class, and gendered identities. By placing Black women at the center of analysis using a Black feminist epistemology, this study aimed to contribute to the sociology of illness and disease literature through analyzing narratives about Black women's experiences with uterine fibroids. Drawing from 31 in-depth qualitative interviews with Black women who have had or do have uterine fibroids, I examined how they frame having this condition. Specifically, this dissertation explores how Black women conceptualize having fibroids and how this impacts their lives, the mechanisms by which Black women cope with and manage fibroids within the context of their lives, how race, class, and gender intersect and influence their illness experiences, and the types of treatment they seek.

### SUMMARY AND DISCUSSION OF RESEARCH FINDINGS

#### *Conceptualizing Uterine Fibroids*

Conrad and Barker (2010) posit that the social construction of illness is shaped by cultural and social systems. Black women's conceptualizations about fibroids are grounded not only in their lived experiences with them, but also their race, class, and gendered identities. In medical terms, fibroids are defined as "benign tumors of the uterus." Several women in the study also describe them as tumors; however, most women also define fibroids in terms of their symptomatic experiences, and the emotional and functional impact of fibroids on their lives. Fibroids represent "a painful problem," they are "embarrassing," "a nuisance," "an abnormality," and "a challenge" that plays a major role in their daily lives. Women conceptualize fibroids to be not as severe or damaging as other illnesses like cancer or stigmatizing like HIV/AIDS, but as a condition that greatly impacts their lives, their fertility, and their psyche.

Furthermore, women's ideas about fibroid ideology are also centered around issues that are unique to Black women. Participants believe that fibroids develop because of genetics, the historical implications of being a Black woman in the United States, and systemic factors associated with class. They also feel that Black women experience unique stressors on a regular basis, and this stress also contributes to the development of fibroids. Additionally, fibroids are thought to develop due to Black women's unhealthy diets and the tendency to be overweight. Examining conceptualizations about fibroids from the perspective of Black women illustrates how the meaning of illness is relevant to one's lived experiences, and race-gendered identities.

Previous studies, as described in chapter two, about uterine fibroids have been largely epidemiological and clinical. They have tried to identify the cause of uterine fibroids and the reason behind the disparate rate and adverse symptoms for Black women compared to others. Qualitative studies such as that done by Askew (2009), Nicholls and colleagues (2004), and Lally (2007) have provided some context around treatment decisions and how women understand and experience fibroids, but all three studies lacked an intersectional analysis and an adequate sample of Black women. The main reason for this study was to incorporate Black women's perspectives into these narratives since they are the ones who are disproportionately affected by fibroids.

The studies by Askew (2009) and Lally (2007) did not assess how women conceptualize uterine fibroids. As learned from this study, how women conceptualize fibroids is central to how they decide to treat their fibroids. In the London study by Nicholls and colleagues (2004), respondents were asked what they understood to be the cause of their fibroids, but this was not discussed in their findings outside of whether or not they felt fibroids were an illness. Similar to women in the Nicholls et al. (2004) study, Black women in this study do not consider fibroids to be an illness. By using an intersectional analysis and focusing on the experiences of Black women, not only are we able to understand that fibroids are conceptualized based on women's lived experiences, but that Black women believe fibroids develop due to their race, class, and gendered identities.

Janet Shim's (2005, 2010) research about the conceptual divide between lay knowledge and epidemiologists is relevant in the discussion about how fibroids are conceptualized. Epidemiological studies about fibroids have not yet determined a definitive etiology for why fibroids develop, or why Black women are disproportionately affected by the condition. While studies have found associations between social factors that are indicative of race, class, and gendered identities, such as perceived racism (Wise et al. 2007), and stressful life events (Vines et al. 2010), the quantitative studies are unable to provide a much needed context about how and why these might be associated with developing fibroids. For example, Vines and colleagues (2010) acknowledged that the measurement of major life events (i.e. job loss, major accidents, operations or illness, new romantic relationships, divorce/break-up, etc.) would most likely differ for non-white women. They found that the number of major life events was positively associated with fibroids, but this association was stronger among white women compared to Black women. This study revealed that other factors are more salient for Black women such as the daily stress of being a Black woman who nurtures and cares for everyone. Shim (2005) suggests that epidemiologists can learn from lay knowledge claims among people who are affected by particular illnesses such as CVD. I argue based on this study that epidemiologists and other medical researchers can also benefit from knowledge claims made by Black women about uterine fibroids.

### *Experiencing Uterine Fibroids*

Most women are affected by symptoms of fibroids, which include frequent urination due to bladder pressure, spontaneous bleeding, and anemia; with the most pervasive symptoms being pain and heavy bleeding. These experiences negatively impact their quality of life by creating added stress, influencing their work lives, and in some cases affecting their ability to conceive and have safe pregnancies. Despite the impact of these fibroid symptoms, most women "keep it moving," by pushing through the pain and employing other coping strategies. The reasons for keeping it moving are associated with women's race, class, and gender. Symptomatic women in this study keep it moving

because they do not have time off from work, want to avoid negative stereotypes about Black women in the workplace, do not want to be defined by their fibroids, and were socialized to be strong Black women even when ill. They cope with fibroid symptoms by doubling up with reinforcements for bleeding, carrying emergency kits, and in some cases isolating themselves during their menstrual cycles.

In her qualitative thesis about quality of life for women suffering from uterine fibroids, Olivia Lally (2007) captured experiences related to the physical, emotional, family, and work affects of fibroids. Her sample included eight middle-class white women, and only included experiences about hysterectomies or “wait and see” as treatment options (Lally 2007). Additionally, she did not have any narratives about the impact on fertility or pregnancy complications as it relates to fibroids. Nicholls et al. (2004) also described similar affects on quality of life, but their study was also among mostly white women and took place in London. The present study includes similar narratives about the diminished quality of life as a result of fibroids and not only includes the perspective of Black women, but also shows how these experiences are race-gendered. The impact of fibroids on fertility and pregnancy was a major part of the illness experience for Black women as evidenced through narratives in this study.

### *Treatment Decisions*

Treatment decisions for uterine fibroids among Black women in this study highlight three major themes – preserving fertility, discomfort with surgery, and the desire to find a permanent solution. Women, who want to have children but have not yet been able, struggle the most with making a treatment decision. Black women seek particular treatment options, not just to preserve fertility, but also to avoid invasive procedures. Non-invasive options include CAM, medication, and “waiting and seeing.” Lastly, some women in the study also pursue more permanent treatments by getting hysterectomies. Even at the cost of never being able to bear children, having a life free of pain and worry is more important. Some treatment decisions are restricted by class status and whether or not one has health insurance, but other social factors are more salient in their treatment decisions than their race, class, and gendered identities.

The present study contributes to literature about treatment decisions for fibroids because it includes discussions about the variety of options that are available. Askew's (2009) study was primarily focused on a comparison of those who had a hysterectomy or myomectomy in the last 2 years. This dissertation includes women's experiences with myomectomy, hysterectomy, UFE, medication, and CAM. Askew (2009) also called for future studies to incorporate Black women's experiences and discuss how symptoms influenced treatment decisions, which is what this study also contributes. Additionally, the present study does not limit the treatment experiences to within the last 2 years, which allows for a discussion about the change in treatment options over time, and the recurring nature of fibroids that often cause women to make more than one treatment decision.

#### *Patient Agency and Black Feminism*

Patient agency is prominent among Black women who have fibroids. In this study patient agency is defined as a woman's power to manage her own health through various acts that allow her to be actively involved in her wellness, and better informed when interacting with medical professionals. The intersectional analysis reveals a framework through which Black women with fibroids engage in health activism by becoming advocates for their own health and empowered patients that are influenced by their race-gendered identities. Participants exert patient agency through health information-seeking to become informed patients in the clinical setting. Through a *sisters helping sisters* strategy, they receive and share knowledge and experiences with other Black women about fibroids in order to fill the void of information received from medical professionals. In the tradition of Black feminist activism, women also exert patient agency in the clinical setting through seeking different doctors and communicating discomfort.

As discussed in chapter seven, sociological research on patient agency has focused on the doctor-patient interaction and the benefits of exerting patient agency in the clinical setting. People who exert patient agency are active in negotiating treatment plans; informed and active patients have better

health outcomes, receive more information, and have more positive doctor-patient interactions (Costello and Roberts 2001; Greenfield et. al 1985; Greenfield et al 1988). Askew (2009) and Nicholls and colleagues (2004) also found that women were proactive about researching on their own, shopping for doctors, and trying home remedies in an effort to gain control over their symptoms. This study contributes to research on patient agency and medical authority by analyzing the specific encounters of Black women in the gynecological setting, and illuminating the traditional mechanisms Black women employ through health activism. By using a Black feminist epistemology and applying an intersectional lens throughout this analysis, we are able to see the importance of patient agency and how it is linked to Black feminist thought through acts of resistance both in and outside of the clinical setting. This research contributes to literature about patient agency and the use of Black feminist epistemology in medical sociological research.

#### RESEARCH IMPLICATIONS

A sociological analysis of experiences with uterine fibroids has not been conducted, to my knowledge. The few qualitative studies about fibroids were completed by researchers in the fields of psychology (Nicholls et al. 2004), child and family development (Askew 2009), and nursing (Lally 2007). From biomedical and epidemiological perspectives, and through several quantitative studies, fibroids have been well investigated in terms of measuring their associated risk-factors (increased estrogen, overweight, reproductive history). In terms of disparities between Black and other women, the research from the Black Women's Health Study has also been fruitful. However, given what is known about the disproportionate rate of diagnosis, and more severe symptoms among Black women, the present study is the only scholarly work that specifically examines how uterine fibroids impact Black women's lives from a Black feminist perspective and using qualitative methods. Aside from addressing the lack of in-depth qualitative analysis about Black women's experiences with fibroids, there are theoretical and sociological implications for this research as well.

### *Sociological Implications*

Uterine fibroids represent a biological condition with social consequences. Black women occupy a unique social location in society as evidenced by their race, class, and gendered identities. Therefore Black women provide an important perspective from which to analyze the social and personal experiences of a medical condition that disproportionately affects them. The study utilizes and contributes a Black feminist epistemological perspective to the field of medical sociology by placing Black women at the center of analysis. Medical sociology can benefit from the inclusive and more subjective nature of a Black feminist epistemology. Studies that incorporate this framework into data collection and analysis might elicit more nuances about health and health disparities that are race, class, and gendered. Conceptualizations and experiences of fibroids, treatment decisions, and patient agency are all influenced by intersecting identities and emphasizes the importance of considering the socio-historical relationship between Black women and medicine.

This study revealed that issues related to Black women's history with medical abuse, discrimination in healthcare, and medical mistrust might not be as relevant today for Black middle-class women, who have greater autonomy over their healthcare and the number of available options for treatment. Granted, autonomy does vary by class as seen with a few women in this study, but these women ultimately had access to care, and the choice of their preferred treatment. The narratives would have been undoubtedly different for Black women from lower class levels. Given the patient agency and autonomy that Black women have illustrated in this study, there are implications for studies as it relates to the sociological concept of biomedicalization. There has been a societal shift from medicalization – “the processes through which aspects of life previously outside the jurisdiction of medicine come to be construed as medical problems” (Clarke et al. 2003:161) – to biomedicalization. In biomedicalization, “medicalization is intensifying, but in new and complex, usually technocientifically enmeshed ways” (Clarke et al. 2003:162). During this era of biomedicalization, individuals are more responsible for their



health “through improved access to knowledge, self-surveillance, prevention, risk assessment, the treatment of risk, and the consumption of appropriate self-help/biomedical goods and services” (Clark et al. 2003:162). However, not everyone has access to the same resources and autonomy differs by race, class, and gender, thus creating a need for “case studies that attend to the heterogeneities of biomedicalization practices and effects in different lived situations” (Clarke et al. 2003:185). Stratified biomedicalization then describes the complex process of the ever-expanding technoscientific interventions that can bypass people due to their race, class and gendered identities (Clarke et al. 2003). The present study offers a case study through these narratives of Black women who have uterine fibroids and how they exert patient agency in this era. Additionally, the disproportionate rate of hysterectomy for fibroids among Black women compared to other women, despite all of the new procedures available, is particularly concerning because it may represent stratified biomedicalization.

Relatedly, despite the fact that fibroids disproportionately affect Black women more adversely than any other racial/ethnic group, a lot of research has primarily been done among studies using mostly white women. Prominent medical sociologist Steven Epstein has discussed the significance of considering who is included in the research process, and why. His “inclusion-and-difference paradigm” for biomedical research and clinical trials explains:

The name reflects two substantive goals: the inclusion of members of various groups generally considered to have been underrepresented previously as subjects in clinical studies; and the measurement, within those studies, of differences across groups with regard to treatment effects, disease progression, or biological processes. (Epstein 2007:6)

The inclusion-and-difference paradigm has implications for research among racial ethnic minorities as it relates to health disparities. Identifying racial differences in disease creates a tendency to routinely uncover questionable associations between race and medical outcomes. For example, as described in previous chapters, fibroid development is associated with increased estrogen, Black race, BMI, and nulliparity. As far as differences between Black and white women, studies have found that reproductive

history and obesity do not explain the racial difference for Black women. Other studies found higher levels of ovarian hormones among Black women that *may* explain the difference between Black and white women. These differences are all biological and measured through associations; and correlation does not equal causation. Epstein (2007) posits that racial differences attributed to biology and genetics have the potential to mask the root causes of health disparities, which are actually influenced by social and cultural factors (Epstein 2007). Some studies have attempted to make associations between fibroids and social factors (i.e. major life events, discrimination), but the fact remains that the etiology of fibroids is unknown and the racial differences cannot be explained. At least by placing Black women at the center of analysis we are able to uncover context around some of the aforementioned associations, how fibroids are experienced, and how treatment is determined among those most impacted by the disparity.

Lastly, this study contributes to what Timmermans and Haas (2008) call, the sociology of disease where, “Rather than contributing to a sociology of chronic illness, such a disease-centered approach allows us to contribute to a sociology of diabetes, asthma, or whatever disease we investigate” (Timmermans and Haas 2008:661). Debating about whether or not fibroids are real, or how they came to be a diagnosable condition is not important. For this study, a sociology of disease perspective takes into account the meaning of illness and how it differs based on severity and symptoms. This analysis contributes to the literature, a “sociology of fibroids,” that takes into account the meaning and experiences of fibroids for Black women specifically. Moreover, women’s ideas about fibroid etiology contribute to research in public health and assessing the social determinants of health, the social and economic factors and conditions that affect the health and well-being of people and communities (WHO 2007). Furthermore,

Lifestyle and behavioral factors do not fully explain health disparities. In addition, such an approach often implicitly ignores the ways in which such lifestyle and behavioural factors are themselves products of the social environment. The increased risk associated with such individual-level social characteristics is structured by larger social forces, such

as patterns of consumption, residential and commercial development, and public policy” (Timmermans and Haas 2008: 667).

If future research did confirm that the disparate rate of fibroids in Black women resulted from their race, class, and gendered identities, then further discussions would be needed about how women could prevent, manage, and treat fibroids considering the magnitude of those social factors.

### *Applied Implications*

In an applied setting, this research is valuable in that as a public sociologist and public health scientist, I offer an interdisciplinary perspective about Black women’s experiences with uterine fibroids. Public sociology entails bringing sociology into a “conversation with the publics,” where research and writing transcend the academy (Burawoy 2005). This dissertation is not meant to simply theorize about Black women’s experiences, but to offer a framework for researching Black women’s health issues for public health and medical practitioners, as well as medical sociologists. Their accounts are important for medical practitioners treating Black women with fibroids to better understand how the decisions for non-treatment or desire to avoid hysterectomies are rooted in race, class, and gendered identities and experiences. As some women described, there was a lack of information provided by their doctors about treatment options. Instead of first offering less-invasive procedures, some women were steered toward hysterectomies or other invasive surgeries when other options were available to them. By exploring aspects of both structure and agency, the study may lead to structural changes in the way gynecologists interact with their patients regarding decision-making for treatment of uterine fibroids. For example, since it is known that Black women have a predisposition to uterine fibroids, why are they not screened and monitored from their first gynecological visit throughout the life course? By detecting them early, women can think more critically and prepare for life plans accordingly, i.e. family planning.

Also with regard to medical professionals treating Black women with fibroids; this study revealed that a lot of women have a preference for female gynecologists, but just as many women have no race or gender preference at all. What is more important for medical practitioners to take away from

this study is that Black women desire more information about fibroids from their doctors, more information about treatment options, to be listened to and respected, and to be treated like a person not a number. These are attributes that all women seeking medical care would most likely prefer. However, this study allowed Black women's perspective on the doctor-patient encounter to be heard, which has been lacking in previous research on clinical encounters.

Grassroots efforts should be employed to address the lack of information about fibroids in the Black community and increase awareness. In an effort to introduce women to less invasive procedures, local doctors have instituted campaigns (John Lipman's "Got Fibroids?" and wearwhitepants.com campaigns) to address fibroids among Black women through procedures like UFE. In the past five years in Atlanta, I have seen outreach initiatives at Black churches, community events, and Internet blogs, about the benefits of UFE. However, often omitted are the stories about unsuccessful attempts at UFE and the fact that this procedure is less effective for younger women (Tropeano, Di Stasi, Amoroso, et al. 2012). This study revealed that there are implications for each procedure that would be better explained and understood in the context of families or informal transfers of lay information (sisters helping sisters).

There are some useful lay resources related to black women and fibroids, such as *It's a Sistah Thing* by Monique Brown (2002) which gives a lot of advice from a "girlfriend's" perspective, and Queen Afua's (2002) book, *Health Thyself for Health and Longevity* is about Black women's wellness overall with specific sections devoted to natural remedies for fibroids (mainly a vegan diet). I have seen articles in Black women's magazines (i.e. Essence and Ebony) about fibroids, and they are often the topic of discussion on Black radio stations, Facebook pages, and various Internet blogs. As an example of sisters helping sisters, a conversation ensued in June 2012 on the Atlanta Black Girls Run Facebook page when a runner reached out for more information about fibroids and treatment options. Instantly, more than 50 women offered their stories or advice to the young lady, including myself. It drew attention to the magnitude and importance of this type of support for Black women who have uterine fibroids.

To enhance the sisters helping sisters ideology, strategies that may be helpful might include a National Association for Black Women and Fibroids, but some participants in this study expressed that this is not necessary. I have a mixed opinion. On one hand it would bring more national attention to the problems Black women face with this issue, open avenues for Black women to discuss how fibroids impact their lives, and serve as a platform for funding and research initiatives. However, on the other hand, there are organizations dedicated to the health of Black women, such as The National Black Women's Health Project, presently known as the Black Women's Health Imperative (<http://www.blackwomenshealth.org/>), which could stand to incorporate more discussions around fibroids (not at all mentioned on their website). After all, it's founder, Byllye Avery is the one that started the "self-help ideology" as it relates to health issues and Black women helping one another. Brown (2002) also mentions the importance of using existing, and creating new, support groups that focus on Black women and fibroids.

Alternatively, a more comprehensive route might be to improve the health education of children as they matriculate through primary and secondary education. Fibroids are common among all women. As children learn about the reproductive system in their health or sexuality classes, they should also learn about common gynecological conditions, such as uterine fibroids. An holistic approach to health education should include educating young girls – I think high school age would be appropriate – about how to have open conversations with their mothers about sexuality and other gynecological concerns. This would create a culture of healthy discussions about womanhood, sexuality, and reproductive health between parents and their children, thus eliminating the communal void that women identified in this study. According to a CDC report, a comprehensive health education curriculum includes, "a variety of topics such as personal health, family health, community health, consumer health, environmental health, sexuality education, mental and emotional health, injury prevention and safety, nutrition, prevention and control of disease, and substance use and abuse," and should be taught by

qualified trained teachers (Collins, Goodman, Moulton 2008:84). However, in 2006, 85% of states adopted policies that teach at least 1 of the 14 topics. The one topic commonly taught across elementary, middle, and high schools was related to alcohol and other drug use prevention (Collins, Goodman, Moulton 2008). Ensuring that young women and girls have appropriate and comprehensive reproductive health education would better equip all women in the future with better knowledge about their health that they can also share with family and others.

Some women in this study believe that fibroids develop as a result of their unique stressors in life and their diet. Additionally, they revealed increased social costs associated with having uterine fibroids that are related to work and interpersonal relationships. Historically, Black women engage in multiple strategies to resist oppression and the controlling images placed on them by society, and engage in coping behaviors to avoid being stereotyped. However these coping strategies can have dire consequences as evidenced through the weathering hypothesis (Geronimus 1996). While policies to address the economic, racist, and sexist experiences that Black women face would be ideal, it is unlikely that they will be implemented. So Black women must remain cognizant of their limits, their bodies, and the implications of “keeping it moving” on their health. As more Black women become aware of their fibroids, establishing a strong sense of patient agency is crucial to maintaining control over one’s reproductive health in an era where fibroids are the leading indicator of hysterectomy.

#### DIRECTIONS FOR FUTURE RESEARCH

While the questions used in this study were broad and covered several topic areas, Black women in this study were more inclined to talk about their symptoms and impact on quality of life, which was very important in the context of their daily lives, but their reflections only touched the tip of the iceberg with regards to their experiences in the healthcare setting. Future research among Black women as health consumers should explore in more detail the experiences between doctors and patients not only with regards to fibroid treatment, but also how Black women navigate the healthcare system in general.

Studies that are more observational and longitudinal would better capture the recurring nature of fibroids and how their experiences with doctors change over time and the long-term impact of their treatment decisions. For example, through keeping in touch with some participants, I know that their struggle continues with regards to choosing a treatment option while also managing severe symptoms, and daily life responsibilities. Additionally, fibroids are the leading indication of hysterectomies, and for some who had hysterectomies at a young age, adequate psychological, emotional, and physical follow-up care has not been provided. Dealing with the hormonal and psychological repercussions of a hysterectomy at the age of 45 is very different for a 35 year old who has not had children. Following these women over time as they traverse this unknown territory would provide insight into post-op care for younger women who have had hysterectomies for fibroids.

Relatedly, more research should be conducted among gynecologists as it relates to treating Black women who have fibroids, as well as homeopathic doctors and practitioners of CAM. Some questions remain unanswered, as access to care should improve for all with the passing of the Affordable Care Act and mandatory health insurance for all. What are medical professionals being taught today regarding screening for fibroids, or how to enhance the doctor-patient relationship? What are gynecologists' and CAM providers' perceptions about the care they provide to Black women with fibroids? What types of conversations are had about fertility and treatment options for fibroids? What do health professionals think about fibroids and Black women? How do physicians feel about the informed Black female patient who is an advocate and agent for her own health?

Black feminist epistemology provides a great framework from which to base a research project about Black women, how the researcher should engage with participants, and how to frame research findings. Nevertheless, there is much needed work in the development of the methodological steps to take during data analysis while using an intersectional framework. As intersectional researchers have declared before, thinking intersectionally and actually applying it to an analysis are very difficult, and the

details of those steps are rarely talked about in depth. Choo and Ferree (2010) offered a framework for researchers doing intersectional work that used examples from prominent studies to articulate their points. However, I was left needing more guidance for my analysis. I found it difficult to ask myself the appropriate analytical questions during data analysis. I also feel that there should be more step by step guides like that provided by psychologist Lisa Bowleg (2008), about how to elicit intersectional responses from participants during data collection. Methodological papers that address these issues would be beneficial.

## CONCLUSION

Uterine fibroids, while considered medically to be a benign condition, disproportionately impact Black women with regard to earlier diagnoses, more severe symptoms, and an increased likelihood for having a hysterectomy. In their narratives of illness we learned how this condition impacts their lives and why their experiences are compounded by their social locations, but we also learned how their resilience and acts of resistance allow them to cope with symptoms through their wellness narratives. This study challenges physicians to be more interactive with Black women about their treatment decisions and understand their underlying concerns about invasive surgeries. It also provides Black women with accounts of others' experiences in hopes that Black women will be more informed about their options, more conversational about gynecological issues with family and friends, and more engaged in the management of their healthcare.



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**APPENDICES****APPENDIX A: IRB APPROVAL LETTER****INSTITUTIONAL REVIEW BOARD**

**Mail:** P.O. Box 3999  
Atlanta, Georgia 30302-3999  
**Phone:** 404/413-3500  
**Fax:** 404/413-3504

**In Person:** Alumni Hall  
30 Courtland St, Suite 217

March 21, 2012

Principal Investigator: Harvey, Adia M

Student PI: Ranell Myles

Protocol Department: Sociology

Protocol Title: Unbearable Fruit: Black Women's Experiences with Uterine Fibroids

Submission Type: Protocol H12338

Review Type: Expedited Review, Category 6, 7

Approval Date: March 21, 2012

Expiration Date: March 20, 2013

The Georgia State University Institutional Review Board (IRB) reviewed and approved the above referenced study in accordance with 45 CFR 46.111. The IRB has reviewed and approved the research protocol and any informed consent forms, recruitment materials, and other research materials that are marked as approved in the application. The approval period is listed above.

Federal regulations require researchers to follow specific procedures in a timely manner. For the protection of all concerned, the IRB calls your attention to the following obligations that you have as Principal Investigator of this study.



1. For any changes to the study (except to protect the safety of participants), an Amendment Application must be submitted to the IRB. The Amendment Application must be reviewed and approved before any changes can take place
2. Any unanticipated/adverse events or problems occurring as a result of participation in this study must be reported immediately to the IRB using the Unanticipated/Adverse Event Form.
3. Principal investigators are responsible for ensuring that informed consent is properly documented in accordance with 45 CFR 46.116.
  - The Informed Consent Form (ICF) used must be the one reviewed and approved by the IRB with the approval dates stamped on each page.
  - A Waiver or Alteration of Consent has been approved for this study in accordance with the requirements set forth in 45 CFR 46.116 d.
  - A Waiver of Documentation of Consent has been approved for this study in accordance with the requirements set forth in 45 CFR 46.117 c.
4. For any research that is conducted beyond the approval period, a Renewal Application must be submitted at least 30 days prior to the expiration date. The Renewal Application must be approved by the IRB before the expiration date else automatic termination of this study will occur. If the study expires, all research activities associated with the study must cease and a new application must be approved before any work can continue.
5. When the study is completed, a Study Closure Report must be submitted to the IRB.

All of the above referenced forms are available online at <https://irbwise.gsu.edu>. Please do not hesitate to contact Susan Vogtner in the Office of Research Integrity (404-413-3500) if you have any questions or concerns.

Sincerely,



Cynthia A. Hoffner, IRB Vice-Chair

**Federal Wide Assurance Number: 00000129**

## APPENDIX B: INFORMED CONSENT FORM

Georgia State University  
Department of Sociology  
**Informed Consent**

Title: Unbearable Fruit: Black Women's Experiences with Uterine Fibroids

Principal Investigator: Adia Harvey Wingfield

Student Principal Investigator: Ranell Myles

I. Purpose:

You are invited to participate in a research study. The purpose of the study is to learn about social and personal experiences of Black women with uterine fibroids. You are invited to participate because you are a Black woman who has fibroids.

II. Procedures:

If you decide to participate, you will be interviewed by Ranell Myles, a graduate student at Georgia State University. Ranell will ask you basic questions about your life (age, marital status, etc) and about your experiences with uterine Fibroids. Interviews will take place in the location of your choosing and will be audio recorded and later transcribed. Interviews are expected to last about one and a half hours.

III. Risks:

In this study, you may or may not experience some emotional stress in talking about your experiences with uterine fibroids.

IV. Benefits:

Participation in this study may or may not benefit you personally by sharing. The study may benefit society by shedding light on the experiences of Black women with fibroids and their interaction with the health care system. Overall, Ranell hopes to gain information about your experiences.

V. Voluntary Participation and Withdrawal:

Participation in research is voluntary. You will not receive money or gifts for your participation. If you decide to be in the study and change your mind, you have the right to drop out at any time. You may skip questions or stop participating at any time. Whatever you decide, you will not lose any benefits to which you are otherwise entitled.

VI. Confidentiality:

Dr. Wingfield and Ranell will have access to the information you provide. We will keep your records private to the extent allowed by law. Information may also be shared with those who make sure the study is done correctly (GSU Institutional Review Board or the Office for Human Research Protection

(OHRP)). We will use false names rather than your name on study records. You may choose your false name. The information you provide will be stored on a password and firewall-protected computer, and stored in a locked file cabinet. Audio files recorded of interviews will be deleted once interviews are transcribed. Your name and other facts that might point to you will not appear when we present this study or publish its results. The findings will be summarized and reported in group form. You will not be identified personally.

VII. Contact Persons:

Please contact Dr. Adia Harvey Wingfield at [aharvey@gsu.edu](mailto:aharvey@gsu.edu)/404 413 6509 or Ranell Myles at [rmyles1@student.gsu.edu](mailto:rmyles1@student.gsu.edu)/404 913 0812 if you have questions about this study. If you have questions or concerns about your rights as a participant in this research study, you may contact Susan Vogtner in the Office of Research Integrity at 404-413-3513 or [svogtner1@gsu.edu](mailto:svogtner1@gsu.edu).

VIII. Copy of Consent Form to Subject:

I will give you a copy of this consent form to keep.

If you are willing to volunteer for this research, and be audio recorded, please sign below.

\_\_\_\_\_  
Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Principal Investigator/Researcher Obtaining Consent

\_\_\_\_\_  
Date

**Are you a  
Black  
woman?**



**Do/did you have uterine fibroids?**

## Share your experiences!

## ★ Research Participants Needed ★

## Purpose\*

- To explore Black women's social and personal experiences with uterine fibroids
- Amplify Black women's voices about their bodies and healthcare

## Eligibility

- Black woman
- Age 18 and above
- Medically diagnosed with uterine fibroids
- Have 1-1 ½ hours to be interviewed
- Live in Atlanta area

## Benefits\*\*

- Help educate medical and sociological researchers about the unique experiences and needs of Black women.

\*Study is being conducted for a dissertation in sociology at Georgia State University

**\*\*There will be NO monetary compensation available for your participation in this study**

**Please contact Ranell Myles, MPH:**

**(404) 913-0812 • rmyles1@student.gsu.edu**

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## APPENDIX D: RECRUITMENT EMAIL MESSAGE

**Subject:** Research Participants needed for study about Black Women's Experiences with Uterine Fibroids

**Email Content:**

**PURPOSE:**

To explore Black women's social and personal experiences with uterine fibroids and give Black women a voice as it pertains to their bodies and medicine.

**ELIGIBILITY:**

1. Black woman
2. Age 18 and older
3. Medically diagnosed with uterine fibroids
4. Have 1-1 ½ hours to be interviewed

**BENEFITS:**

Help educate medical and sociological researchers about the unique experiences and needs of Black women who have uterine fibroids.

**CONTACT:**

Please contact Ranell Myles to participate @ (404) 913-0812 or [rmyles1@student.gsu.edu](mailto:rmyles1@student.gsu.edu)

**ADDITIONAL INFORMATION:**

This study is being conducted for a dissertation in sociology at Georgia State University and there will be no monetary compensation available for your participation.

## APPENDIX E: DEMOGRAPHICS SURVEY &amp; INTERVIEW GUIDE

**Demographics Survey & Interview Guide****Demographics Survey**

Thank you so much for agreeing to participate in this study. First, I think it's important that I explain why this study is so important to me. I myself was diagnosed with uterine fibroids in 2007 and have had an interesting journey myself with my own symptoms, concerns, and with doctors. My interactions with the healthcare system are what sparked my investigation into other Black women's experiences.

The questions I have are about your experiences with uterine fibroids. Some questions are broader than others so that you can interject ideas that I have not considered. Please feel free to introduce issues that are relevant to your particular experience. Our interview will be tape-recorded and I will take notes during our conversation

Do you have any questions before we get started?

**SCREENING**

To begin, I need to verify your eligibility for this study.

1. Have you been diagnosed with uterine fibroids by a medical professional?
2. Would you consider yourself to be Black or of African descent?

*(If respondent answers "no" to either question, they will be told they are ineligible for study, will be thanked for their time and asked to refer other potential participants to contact the researcher)*

**GENERAL DEMOGRAPHICS**

Now I'm going to ask you a couple of questions about you to get a sense of who you are, where you've come from, and where you're going.

1. What is your age?
2. Where were you born and where did you grow up?
3. What is your ethnicity? Would you identify yourself as American? If not how would you identify yourself? *(An ethnic group is a group of people whose members identify with each other, through a common heritage, often consisting of a common language, a common culture (often including a shared religion) and/or an ideology that stresses common ancestry or endogamy)*
4. What is your educational background?  
*What is the highest level of education you have attained? (less than HS, HS diploma/GED, some college/AA, BA/BS, Masters, Terminal degree)*
5. What is your sexual orientation?
6. What is your relationship status? For example, are you married, partnered, divorced, widowed, etc?
7. Do you have any children?  
*If yes, how many and what are their ages?*
8. Tell me about your employment status. Are you currently working? What is your occupation? Are you happy in your current field?

9. What is your annual household income?

10. Who lives with you in your household?

11. Do you currently have health insurance?

*If so, what kind, is your insurance private or public? Paid for by your employer or yourself?*

### **FIBROID**

Now, I'm just going to ask you a few questions about fibroids to get a general sense about your knowledge of fibroids. The first question is kind of open ended and then 8 multiple-choice quiz-like questions.

1. Do you feel that you well educated about uterine fibroids?

1. As far as you know, uterine fibroids are

- (a) Endometrial polyps
- (b) Muscular growths in the uterus
- (c) Cancerous tumors
- (d) I am not sure

2. At what ages do you think uterine fibroids are most common?

- (a) Women between the ages of 20 and 30
- (b) Women between the ages of 30 and 40
- (c) Women between the ages of 40 and menopause
- (d) Uterine fibroids are not common

3. In your opinion, treatment for fibroids is recommended

- (a) For most women with fibroids
- (b) Only for women with bothersome symptoms
- (c) For most postmenopausal women
- (d) I am not sure

4. As far as you know, which symptoms are commonly associated with uterine fibroids?

- (a) Heavy or abnormal periods
- (b) Pelvic pressure or pain
- (c) Problems with urinary frequency
- (d) All of the above

5. After menopause, what is likely to happen to uterine fibroids and their symptoms?

- (a) Usually decrease or go away
- (b) Usually stay the same
- (c) Usually increase or multiply

6. As far as you know, which treatment permanently removes fibroids and prevents future fibroids?

- (a) Hysterectomy
- (b) Surgical removal of the fibroids (myomectomy)
- (c) Blocking the blood supply to the fibroid(s) by uterine artery embolization
- (d) Hormone medications
- (e) Pain medications
- (f) I am not sure

7. Do you happen to know which of the following is true about hysterectomy treatment?

- (a) It requires a 1–2 week recovery time for most women
- (b) It has a 3% chance of major complications
- (c) It will not affect a woman's ability to have children
- (d) I am not sure

8. Compared to white women, Black women are...

- (a) 7-8 times more likely to have uterine fibroids
- (b) 2-4 times more likely to have uterine fibroids
- (c) just as likely to have uterine fibroids
- (d) 2-4 times less likely to have uterine fibroids

### **Semi-Structured Interview Guide**

*Now we're going to move into the more in depth questions. It is my intention that our interview feels more like a dialogue as opposed to rigid questions and answers that must be covered.*

#### **GENERAL**

1. Describe fibroids in your own words. *Where do they come from? Why do they occur? What do you understand about the cause of your condition?*

2. When did you first become aware of your fibroids?

3. Tell me about your experiences with uterine fibroids since you were diagnosed, or became symptomatic. *How has your life changed since you were diagnosed with fibroids, or if you experience symptoms, how have they impacted your life?*

4. How long do you expect to have fibroids?

5. Do you classify your having fibroids as having an illness or disease, or neither? Why or why not? Define illness and disease in your own words.

#### **HEALTHCARE**

1. In general, how do you manage your health? What do you do when you are ill, in pain, or injured? *Do you visit a doctor or manage your health in other ways? Where do you go most often for healthcare? (Do you remember the first time you went to a gynecologist? What was the experience like for you and how has it changed over the years? How often do you go to the doctor? How often do you go to the gynecologist?)*

2. Are you currently under the care of a physician or doctor for your fibroids, do you manage them in other ways, or are you not managing them at all? Why or why not? *How often do you do what you do for management?*

3. Are you considering or have you had experiences with any treatment options? Which options? How did you come this decision (or these decisions)? Were you satisfied with your decision or the outcome? Why or why not?

4. Tell me about the role that healthcare providers have played in your life since your diagnosis? What resources, if any did they provide you with or direct you to? What do you feel about the care you've received?



5. Have you participated in any clinical trials for treatment of uterine fibroids? Why or why not?
6. What have been your experiences with your health insurance company (if she has health insurance) regarding you having uterine fibroids?
7. Have you sought alternative treatment methods for your fibroids, such as naturopathic doctors, herbalists, or other complementary and alternative medicine? Why or why not? Explain your experiences. If you did, how did you come to this decision?

### **REPRODUCTIVE HISTORY**

*Now I'm going to ask some sensitive questions about your reproductive history, but it will help me get a better sense of your experiences.*

1. Tell me a little about your reproductive history. When did you first start menstruating? *How many pregnancies, miscarriages, abortions, etc. have you had?*
2. Have your fibroids impacted your reproductive experiences? In what ways? Explain your experiences.

### **SOCIAL**

1. Who else knows about your fibroids? How did they respond when you told them?
2. Whom else do you know with uterine fibroids? Do you have a support network that you use to help with treatment decisions or other reasons? How are these networks used? How did you find these networks?
3. Do you engage/participate in peer networks or social media groups that discuss uterine fibroids?
4. How has your having fibroids impacted your intimate relationships? Sexual experiences?

### **RACE AND GENDER**

1. Did you know that Black women are 2-3 times more likely to have uterine fibroids? What are your thoughts on this disparity? Why do you think this disparity exists?
2. Do you feel that your being a Black women has had an impact on your acquiring fibroids, or your experiences with fibroids? Why or why not? In what ways?
3. Do you consider yourself a feminist? (If they say they don't know what a feminist is, say, "*what does a feminist mean to you?*") *Are you that?*) *Black feminist? Womanist?*

### **CONSEQUENCES**

1. What have been some of the effects of you having fibroids on your everyday life? (work, socializing, everyday activities, relationships, family, friends)
2. What has been the most troubling issue or concern for you in regards to having fibroids? *What is the most difficult aspect of having fibroids?*
3. On a scale of 1 to 10, how would you rate the overall impact of fibroids on your life?

4. Has anything positive come out of your experiences with fibroids?
5. To what extent do you feel that your condition influences how you generally feel?

### **CLASS**

1. Have you had any restrictions in accessing healthcare or other resources associated with managing your fibroids?
2. Since your diagnosis with uterine fibroids, has there been any financial limitations placed on you? Explain. *Has having fibroids been a significant financial burden for you?*
3. How much did the treatment options you engaged in cost? Co-pays, out of pocket surgery costs? How much money overall would you say you spent on fibroid management?

### **SELF**

1. Have you done your own research on uterine fibroids? What did you learn or not learn in this process? Did researching on your own help you in any way?
2. How much control do you feel you have over your condition?
3. What would make the situation better for you? *What would you like to change?*
4. Has having fibroids changed how you feel about your body? In what ways?
5. How would you describe your overall health? Do you have an active lifestyle (history of athleticism?)? Do you eat a balanced diet?

### **OTHER**

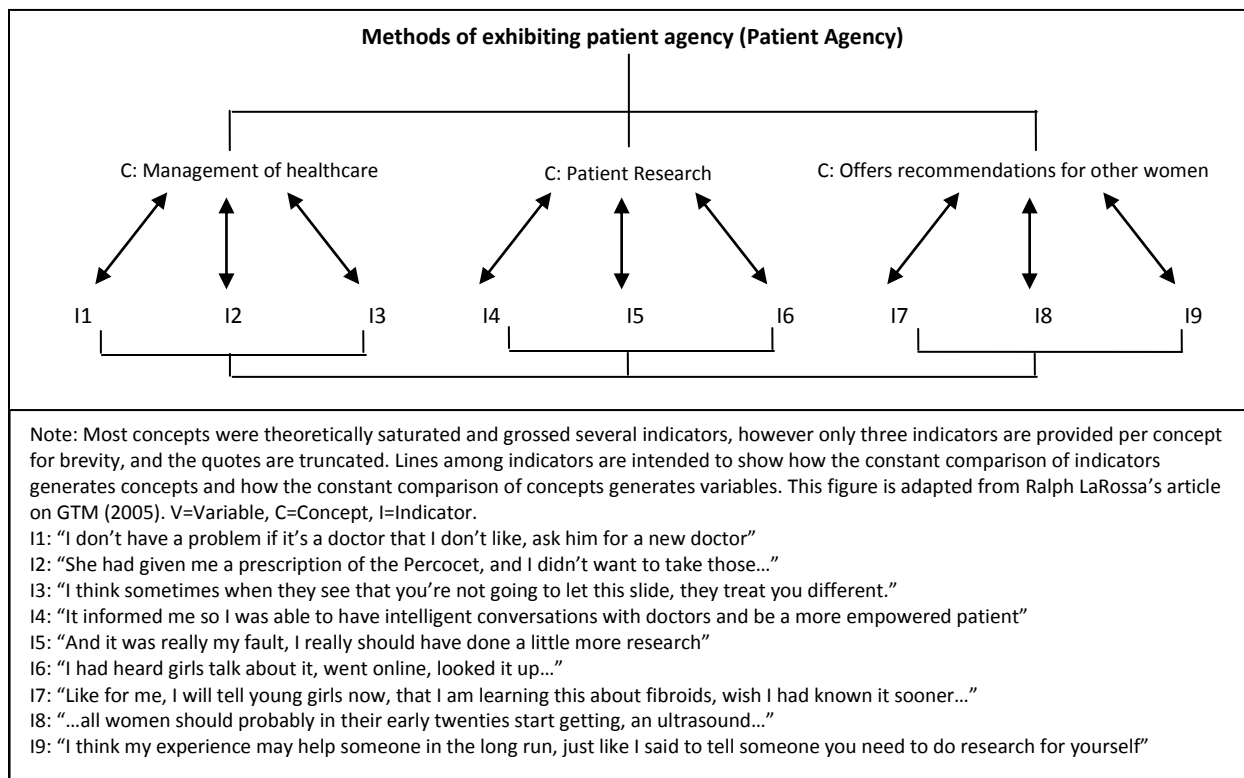
This concludes all the questions I have for you.

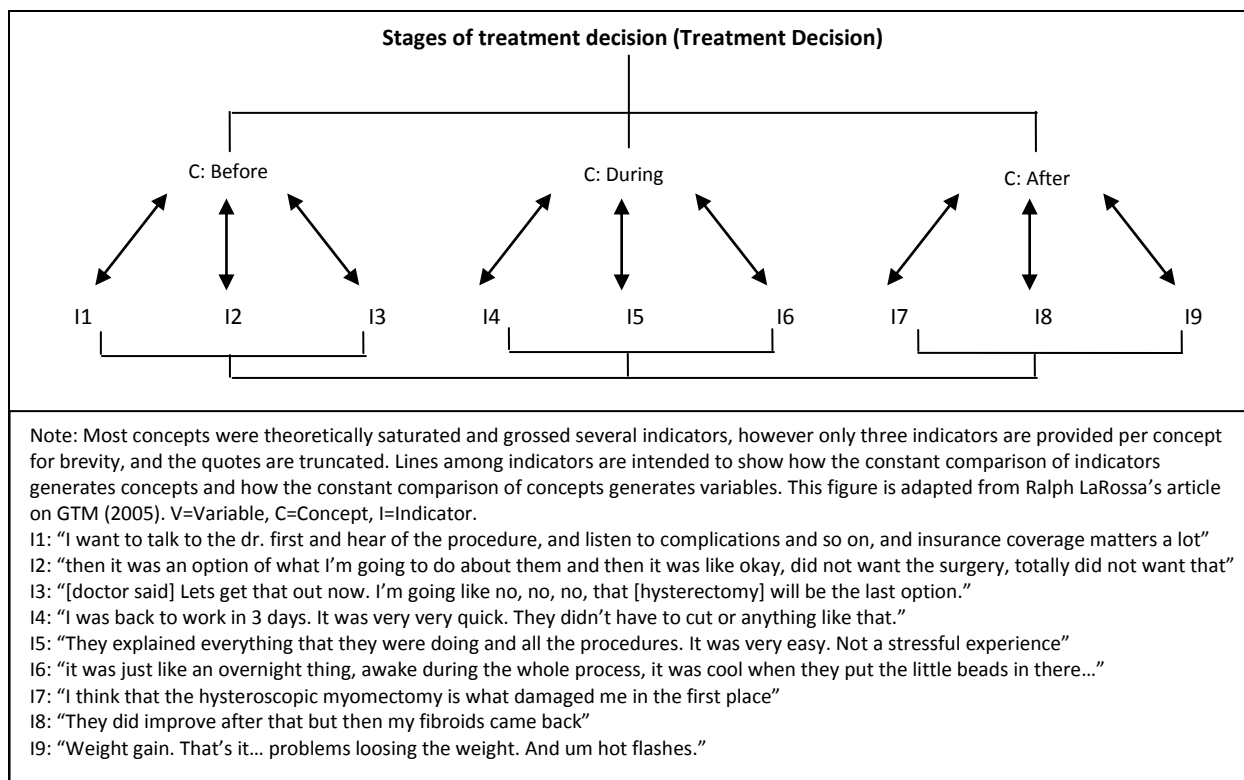
1. Is there anything else you would like to add or share about your experiences?
2. What did you think of the interview? Is there anything you would change or like to see added?
3. Lastly, when I write up my results, I will be using a false name for each participant. Would you like to pick the name that will be used in my write up?

## APPENDIX F: CODING PROCEDURES

### Open Coding

#### Variable-Concept-Indicator Models





## **Axial Coding**

### **Focal Variable: Conceptualizations of Fibroids**

#### **6C's – Causes, contexts, contingencies, consequences, covariances, and conditions:**

1. What are the conditions that give rise to this phenomenon? What causes this phenomenon?

*Patient agency, impact on life, why Black women have fibroids*

2. What is the context in which this phenomenon is embedded?

*Internet medicine, self-help/educated patients, CAM, managed healthcare, Resources (social capital, class status), relationships/support, structure of the healthcare system, and multiple health disparities in Black population. Would these results be different if this were a group of white women?*

3. What are some of the intervening conditions that mediate this phenomenon?

*Conceptualizations of illness/disease, doctor/patient relationship, intersectionality*

4. What are the action/interaction strategies and tactics in which this phenomenon is handled, managed, or carried out?

*Fibroid conversations, definitions/descriptions of fibroids*

5. What are the consequences of these strategies, or what does this phenomenon cause or influence?

*Fibroid knowledge, thoughts about why Black women have fibroids*

6. What are the co-varying variables associated with this phenomenon, if any?

*Beliefs about what causes fibroids in general, thoughts about why Black women have fibroids*

#### **Other Questions:**

How do politics and power play out in social interactions?

*Who defines what fibroids are? What definition is valid?*

*Are conceptualizations of fibroids rooted in their personal experiences with fibroids?*

Who?	Self, support network, doctors
When?	Discovery of fibroids, fibroid conversations
Why?	Symptoms, impact of fibroids on life
How?	Beliefs about causes of fibroids, patient agency (research), gynecological experiences, reproductive history
Consequences?	Thoughts about why Black women are so affected

#### **Thoughts from Memos:**

*-As I code for fibroid definitions, I thought about how to dimensionalize this category. Their definitions could be broken down into physical, emotional, and something else... This participant talks about both physical and emotionally what fibroids are and represent. This could very well be a core variable since one of the research questions is how do Black women conceptualize fibroids. Some see it as a physical manifestation of a mental malady, while others see it as a manifestation of poor health/diet/lifestyles, and others don't see it as anything but a physical ailment*

### Focal Variable: Coping with Fibroids Symptoms

#### **6C's – Causes, contexts, contingencies, consequences, covariances, and conditions:**

1. What are the conditions that give rise to this phenomenon? What causes this phenomenon?

*Impact of fibroids on life, symptoms of fibroids*

2. What is the context in which this phenomenon is embedded?

*Internet medicine, self-help/educated patients, CAM, managed healthcare, Resources (social capital, class status), relationships/support, structure of the healthcare system, and multiple health disparities in Black population. Would these results be different if this were a group of white women?*

3. What are some of the intervening conditions that mediate this phenomenon?

*Access to resources to cope, social capital, support, healthcare seeking behaviors*

4. What are the action/interaction strategies and tactics in which this phenomenon is handled, managed, or carried out?

*How they cope/manage fibroids (abstain from activities, drugs/medication, push through, rest/sleep, reinforcements for bleeding)*

5. What are the consequences of these strategies, or what does this phenomenon cause or influence?

*Treatment decisions, "Keep it moving"*

6. What are the co-varying variables associated with this phenomenon, if any?

*Treatment decisions*

#### **Other Questions:**

How do politics and power play out in social interactions?

Who?	Self
When?	
Why?	Impact of fibroids on life, symptoms
How?	Types of coping
Consequences?	

#### **Thoughts from Memos:**

### Focal Variable: Doctor/Patient Relationship

#### **6C's – Causes, contexts, contingencies, consequences, covariances, and conditions:**

1. What are the conditions that give rise to this phenomenon? What causes this phenomenon?

*Gynecological experiences, symptoms, impact on life, socialization of healthcare, healthcare-seeking behaviors, doctor preference, and intersectionality*

2. What is the context in which this phenomenon is embedded?

*Internet medicine, self-help/educated patients, CAM, managed healthcare, Resources (social capital, class status), relationships/support, structure of the healthcare system, and multiple health disparities in Black population. Would these results be different if this were a group of white women?*

3. What are some of the intervening conditions that mediate this phenomenon?

*Perceptions of doctor's intentions, doctor preference, patient agency, healthcare seeking behaviors*

4. What are the action/interaction strategies and tactics in which this phenomenon is handled, managed, or carried out?

*Conversations with doctors, developing a partnership with the doctor, goes to doctor or doesn't go to doctor, gynecological experiences*

5. What are the consequences of these strategies, or what does this phenomenon cause or influence?

*Wanting more options, doctor preference, doctor recommendations, patient agency, treatment decision*

6. What are the co-varying variables associated with this phenomenon, if any?

*Doctor recommendations*

#### **Other Questions:**

How do politics and power play out in social interactions?

*Who has power here, her or doctor? How much power does she feel she has vs. her actual power (control over fibroids)*

Who?	Self and doctor
When?	
Why?	Coping w/ fibroids, treatment decisions
How?	Type of relationship (positive, negative), socialization of healthcare, healthcare seeking behaviors, healthcare system, gynecological experiences
Consequences?	Doctor recommendations, treatment decisions, patient agency

#### **Thoughts from Memos:**

*-Participant 5 discusses a conflict she has between her loyalty to her Black female OB/GYN but distrust based on her last encounter with her. This is a very interesting display of intersecting identities and the impact on the doctor/patient relationship. She is truly conflicted over not being able to trust her Black female gynecologist anymore, based on their previous interactions. She is currently out of gynecological care. This could be a concept or variable that helps explain why some women stay or leave medical care because of their relationships with their physicians.*

*-Participant 24 talked about the arrogant doctor and I think it's important to talk about how doctors might be arrogant and how there's a fine line in choosing an arrogant competent doctor and someone that's compassionate but may not be as good of a doctor. Participant 9 also talked about her doctor being arrogant and not necessarily having the best bedside manner, but he was really good at what he did.*

*-A few women talk about having condescending doctors and how they alter their choice in doctors from those experiences.*

### Focal Variable: Fibroid Conversations

#### **6C's – Causes, contexts, contingencies, consequences, covariances, and conditions:**

1. What are the conditions that give rise to this phenomenon? What causes this phenomenon?

*Impact on life, symptoms, motherhood vs. treatment options, treatment decisions*

2. What is the context in which this phenomenon is embedded?

*Internet medicine, self-help/educated patients, CAM, managed healthcare, Resources (social capital, class status), relationships/support, structure of the healthcare system, and multiple health disparities in Black population. Would these results be different if this were a group of white women?*

3. What are some of the intervening conditions that mediate this phenomenon?

*Intersectionality/intersecting identities of Black womanhood, motherhood vs. treatment options*

4. What are the action/interaction strategies and tactics in which this phenomenon is handled, managed, or carried out?

*Talking*

5. What are the consequences of these strategies, or what does this phenomenon cause or influence?

*Support for fibroids*

6. What are the co-varying variables associated with this phenomenon, if any?

*Support for fibroids, treatment decisions, coping mechanisms, theories about Black women and fibroids, motherhood vs. treatment options*

#### **Other Questions:**

How do politics and power play out in social interactions?

*They are give and take conversations between people and doctors.*

Who?	Self, family/partners, doctors
When?	
Why?	To share information, to know family history
How?	Chats with family/partners, doctors, sisters
Consequences?	Treatment decisions, coping with fibroids, why Black women so affected, motherhood vs. treatment options, support

#### **Thoughts from Memos:**

*- I think this could be a fairly substantial variable... and can be dimensionalized by types of fibroid conversations... Some women talk about their conversations with family about the history would have been helpful. Some talk about the conversations with friends and other sufferers makes them feel not a lone... This could also be collapsed under coping mechanisms or strategies or something like that. For now I will leave it undimensionalized and maybe change during axial coding.*

*-While coding participant 5, she talked about the modest conversations about talking about breast cancer, and how the perspective changed when someone told her the importance of sharing her story, so they may get tested too. She said fibroids are okay to talk about but why? But it's also okay if she doesn't talk about them because Black women know about them now and their treatment options more than she did when she was younger. This highlights the importance of conversations about diseases and illness in our community to combat health disparities and achieve better health.*

*-Participant 7 talks about feminism and how she is a feminist as it relates to her educating others about fibroids specifically, Black women in particular, through enlightenment of others. Intersectionality.*

*-Similar to the participant with breast cancer, one participant (3) who had thyroid cancer also didn't like to talk about that, and felt that fibroids were "safe to talk about, it's not considered an illness. Women who have experiences with multiple illnesses is also important to talk about when thinking about intersectionality.*



### Focal Variable: Impact of Fibroids on Life

#### **6C's – Causes, contexts, contingencies, consequences, covariances, and conditions:**

1. What are the conditions that give rise to this phenomenon? What causes this phenomenon?

*Symptoms, reproductive history*

2. What is the context in which this phenomenon is embedded?

*Internet medicine, self-help/educated patients, CAM, managed healthcare, Resources (social capital, class status), relationships/support, structure of the healthcare system, and multiple health disparities in Black population. Would these results be different if this were a group of white women?*

3. What are some of the intervening conditions that mediate this phenomenon?

*Support for fibroids, social capital, treatment decision, coping with fibroids*

4. What are the action/interaction strategies and tactics in which this phenomenon is handled, managed, or carried out?

*Fibroid conversations, coping strategies*

5. What are the consequences of these strategies, or what does this phenomenon cause or influence?

*Patient agency, healthcare seeking behaviors, control over fibroids, bodies, relationships with others, impact of fibroids on daily thoughts*

6. What are the co-varying variables associated with this phenomenon, if any?

*Symptoms*

#### **Other Questions:**

How do politics and power play out in social interactions?

Who?	Self, friends, family, co-workers
When?	During menstrual cycle, other times
Why?	
How?	Impacts ability to have kids, intimacy, fatigue, work, finances
Consequences?	

#### **Thoughts from Memos:**

### Focal Variable: “Keep it Moving”

#### **6C’s – Causes, contexts, contingencies, consequences, covariances, and conditions:**

1. What are the conditions that give rise to this phenomenon? What causes this phenomenon?

*Wanting more options, doctor recommendations, treatment decision, symptoms*

2. What is the context in which this phenomenon is embedded?

*Internet medicine, self-help/educated patients, CAM, managed healthcare, Resources (social capital, class status), relationships/support, structure of the healthcare system, and multiple health disparities in Black population. Would these results be different if this were a group of white women?*

3. What are some of the intervening conditions that mediate this phenomenon?

*Doctor/patient relationship, doctor recommendations, intersectionality*

4. What are the action/interaction strategies and tactics in which this phenomenon is handled, managed, or carried out?

*Just push through pain, treatment decision (wait and see), coping with fibroids*

5. What are the consequences of these strategies, or what does this phenomenon cause or influence?

*Treatment decision (satisfaction)*

6. What are the co-varying variables associated with this phenomenon, if any?

*Coping with fibroids, treatment decision*

#### **Other Questions:**

How do politics and power play out in social interactions?

Who?	Self
When?	Discovery of fibroids, when symptomatic
Why?	Wanting more options, doctor recommendations
How?	
Consequences?	

#### **Thoughts from Memos:**

*-It is interesting that women who suffered in their childhood years, suffered through it like this participant (25). She didn't really talk about how severe her symptoms were with anyone. I also linked this to the code etiquette and abnormal normalcy, because it does contribute to the abnormal normalcy that women experience with regards to symptoms and it needs to be discussed more.*

*-Keep it moving reminds me of the Sojourner syndrome (Mullings?) and Weathering (Geronimus 1992)*

*-During axial coding it would be to explore women who are coded as Sojourner and how severe their symptoms were or how many symptoms they had. It seems like women who are more symptomatic, are more likely to have this Sojourner mentality.*

### Focal Variable: Motherhood vs. Treatment Options

#### **6C's – Causes, contexts, contingencies, consequences, covariances, and conditions:**

1. What are the conditions that give rise to this phenomenon? What causes this phenomenon?

*Symptoms, impact on life (ability to have children), wanting more options*

2. What is the context in which this phenomenon is embedded?

*Internet medicine, self-help/educated patients, CAM, managed healthcare, Resources (social capital, class status), relationships/support, structure of the healthcare system, and multiple health disparities in Black population. Would these results be different if this were a group of white women?*

3. What are some of the intervening conditions that mediate this phenomenon?

*Doctor/patient relationship, intersectionality (Black women and motherhood), doctor recommendations, perceptions of doctor's intentions, ideas about womanhood*

4. What are the action/interaction strategies and tactics in which this phenomenon is handled, managed, or carried out?

*Patient agency, fibroid conversations*

5. What are the consequences of these strategies, or what does this phenomenon cause or influence?

*Treatment decision (satisfaction), control over fibroids (over treatment decision)*

6. What are the co-varying variables associated with this phenomenon, if any?

*Treatment decision*

#### **Other Questions:**

How do politics and power play out in social interactions?

Who?	Self, partners
When?	Childbearing years
Why?	To preserve ability to have kids but also alleviate symptoms
How?	Fibroid conversations, doctor/patient relationship
Consequences?	Treatment decision (satisfaction with), control over fibroids (over treatment decision)

#### **Thoughts from Memos:**

*-Participant 11 talked about her fears of the treatment option prescribed and her ability to have children later and the doctor's insensitivity to those fears. This made me change my variable from "Importance of motherhood" to "Motherhood vs. treatment options" because it is this struggle that frequently occurs in these conversations with the women who haven't had children yet or are speaking about when they did not have children yet.*

*-How do family dynamics change?*

### Focal Variable: Patient Agency

#### **6C's – Causes, contexts, contingencies, consequences, covariances, and conditions:**

1. What are the conditions that give rise to this phenomenon? What causes this phenomenon?

*Symptoms, impact on life, doctor recommendations, doctor/patient relationship*

2. What is the context in which this phenomenon is embedded?

*Internet medicine, self-help/educated patients, CAM, managed healthcare, Resources (social capital, class status), relationships/support, structure of the healthcare system, and multiple health disparities in Black population. Would these results be different if this were a group of white women?*

3. What are some of the intervening conditions that mediate this phenomenon?

*Doctor recommendations, intersectionality/intersecting identities, socialization of healthcare, healthcare seeking behaviors, gynecological experiences*

4. What are the action/interaction strategies and tactics in which this phenomenon is handled, managed, or carried out?

*Doctor/patient relationship (conversations, partnership), experiences with healthcare system/insurance companies, fibroid conversations, management of care, and patient research*

5. What are the consequences of these strategies, or what does this phenomenon cause or influence?

*Treatment decision (satisfaction of, decision making process), "keep it moving", doctor/patient relationship, coping strategies, doctor/patient relationship*

6. What are the co-varying variables associated with this phenomenon, if any?

#### **Other Questions:**

How do politics and power play out in social interactions?

*How do the women execute agency with powerful doctors? They speak, seek second opinions, research before choosing a treatment option, they have conversations with friends and families.*

*What types of women have a strong patient agency, and how does that impact their relationships with their physicians, or their treatment decisions? What variables influence the impact of uterine fibroids on these women's lives?*

Who?	Self, doctors, insurance
When?	They want something to change
Why?	So she can be in control of her own health
How?	She manages her care or doesn't, does research, she makes recommendations for other women in similar situations
Consequences?	Satisfaction with treatment decisions, coping with fibroids

#### **Thoughts from Memos:**

*-Try to link patient agency and clinical trial to historical treatment of Black women and gynecology.*

*-Participant 7 talks about feminism and how she is a feminist as it relates to her educating others about fibroids specifically, Black women in particular, through enlightenment of others. Intersectionality.*

*-The fact that some women blame themselves for their inability to have children due to the treatment options they pursued and the patient agency they didn't exercise, is upsetting and highlights the need for improving patient agency among women with fibroids at diagnosis.*

*-Need to incorporate patient agency and doctor/patient relationship into theoretical framework.*

### Focal Variable: Support for Fibroids

#### **6C's – Causes, contexts, contingencies, consequences, covariances, and conditions:**

1. What are the conditions that give rise to this phenomenon? What causes this phenomenon?

*Impact on life, symptoms, treatment decision*

2. What is the context in which this phenomenon is embedded?

*Internet medicine, self-help/educated patients, CAM, managed healthcare, Resources (social capital, class status), relationships/support, structure of the healthcare system, and multiple health disparities in Black population. Would these results be different if this were a group of white women?*

3. What are some of the intervening conditions that mediate this phenomenon?

*Social capital, resources, impact on life, intersectionality/identities*

4. What are the action/interaction strategies and tactics in which this phenomenon is handled, managed, or carried out?

*Engage supporters through dialogue and advice seeking (family, network of others with fibroids)*

5. What are the consequences of these strategies, or what does this phenomenon cause or influence?

*Treatment decisions*

6. What are the co-varying variables associated with this phenomenon, if any?

#### **Other Questions:**

How do politics and power play out in social interactions?

Who?	Self, others
When?	Symptoms or impact on life lead to need for support, treatment decision may require support
Why?	Need emotional, or physical support, need strategies for coping
How?	Family, media, social networks
Consequences?	Treatment decision

#### **Thoughts from Memos:**

### Focal Variable: Symptoms of Fibroids

#### **6C's – Causes, contexts, contingencies, consequences, covariances, and conditions:**

1. What are the conditions that give rise to this phenomenon? What causes this phenomenon?

*Diagnosed with fibroids/discovery of fibroids*

2. What is the context in which this phenomenon is embedded?

*Internet medicine, self-help/educated patients, CAM, managed healthcare, Resources (social capital, class status), relationships/support, structure of the healthcare system, and multiple health disparities in Black population. Would these results be different if this were a group of white women?*

3. What are some of the intervening conditions that mediate this phenomenon?

*Coping with fibroids, treatment decisions*

4. What are the action/interaction strategies and tactics in which this phenomenon is handled, managed, or carried out?

*Coping strategies, treatment decision*

5. What are the consequences of these strategies, or what does this phenomenon cause or influence?

*Impact on life, healthcare seeking behaviors, coping strategies, treatment decision*

6. What are the co-varying variables associated with this phenomenon, if any?

*Impact on life*

#### **Other Questions:**

How do politics and power play out in social interactions?

Who?	Self
When?	During cycle and always
Why?	Because she has fibroids, discovery of fibroids, impact on life
How?	
Consequences?	Impact on life, treatment decision, healthcare seeking behaviors for fibroids

#### **Thoughts from Memos:**

*-The way doctors assesses symptoms is not conducive to the lived experiences of women who are symptomatic. Participant 22 remind me the stupid question doctors always ask, "how many pads do you go through when you're on your period?" It doesn't really provide the doctor with adequate information about experiences of heavy bleeding.*

*-Participant 11 talks about the impact of life stress on Black women's wombs, which is interesting. That we have stress but the effects of it manifest in our wombs, which is sad.*

*-I think it's interesting that (19) brings up this issue that people who experience this "abnormal normal" are not asked about their symptoms. It seems that Black women should be screened more regularly for fibroids and asked about their cycles in a more informative way to be diagnosed early if only to just know that they have this problem and can plan life accordingly.*

*-Intersectionality because her father is an OB/GYN but she didn't tap that resource as a child with heavy painful periods, where she may have had them as a child and didn't know it, or think it necessary to tell her father.*

### Focal Variable: Treatment Decision(s)

#### **6C's – Causes, contexts, contingencies, consequences, covariances, and conditions:**

1. What are the conditions that give rise to this phenomenon? What causes this phenomenon?

*Symptoms, impact on life, support, socialization of health/care, doctor recommendations, motherhood vs. treatment decision, gynecological experiences, and social capital*

2. What is the context in which this phenomenon is embedded?

*Internet medicine, self-help/educated patients, CAM, managed healthcare, Resources (social capital, class status), relationships/support, structure of the healthcare system, and multiple health disparities in Black population. Would these results be different if this were a group of white women?*

3. What are some of the intervening conditions that mediate this phenomenon?

*Patient agency, fibroid knowledge, gynecological experiences, doctor recommendations, intersectionality, doctor/patient relationship, ideas about causes of fibroids, and social capital*

4. What are the action/interaction strategies and tactics in which this phenomenon is handled, managed, or carried out?

*Patient agency (research), fibroid conversations, healthcare seeking behaviors, weighing motherhood vs. treatment options*

5. What are the consequences of these strategies, or what does this phenomenon cause or influence?

*Satisfaction with decision, coping with fibroids, gynecological experiences, patient agency, fibroid conversations, support*

6. What are the co-varying variables associated with this phenomenon, if any?

*Coping with fibroids, doctor recommendations*

#### **Other Questions:**

How do politics and power play out in social interactions?

*Who makes the ultimate decision here? Does she truly have control over her fibroid treatment options?*

Who?	Self, support network, doctor
When?	It's a recurring process
Why?	Impact on life
How?	Weighing motherhood vs. treatment options, patient agency (research)
Consequences?	Coping with fibroids, satisfaction with decision, gynecological experiences, patient agency, fibroid conversations

#### **Thoughts from Memos:**

*-The control patients feel they have over their fibroids and their treatment decisions also plays into the whole patient agency thing and the medical mistrust.*

*-A couple of participants brought up prayer, and faith as a treatment, or in conjunction with doctor recommended treatments. I think this is representative of CAM as well, and I didn't see anything in the literature before about it, but I need to look again.*

*-At this point not sure how to dimensionalize this concept/category. The subcategories are all over the place from actual decisions to the process. Consider types of decision processes or stages.*

## **Selective Coding**

### **Core Variable: Phases of Treatment Decision Making (251 indicators in the data)**

Treatment process captures all things related to the process of deciding to treat for fibroids or not, a little of what the treatment decision was (wait and see, or avoiding/self treating etc.) and what factors were associated with that decision (experiences during and after, impact of decision, satisfaction).

**Questions for me:** Is this really a variable? Does it have dimension?

**Considerations for writing:** Highlights the many ways in which Black women are managing fibroids without surgery or without hysterectomy or invasive operations and why that is not the go to option for them and how they negotiate what they want through patient agency. Explain how their conceptualization of fibroids contributes to their decision making process. How can this be framed to answer the research questions? *"How do Black women frame the condition of having uterine fibroids? Specifically, the study intends to investigate a) how Black women conceptualize having fibroids, b) whether Black women's conceptualizations of fibroids affect feelings about selves or their lifestyles, c) the mechanisms, if any, by which Black women deal with uterine fibroids, d) whether or how their multiple race, class, and gender identities affect the illness experiences and types of treatment, if any, that they seek, and e) how conventional and complementary and/or alternative medicine (CAM) shape Black women's experiences with uterine fibroids."*

### **These subcategories all contribute to the treatment decision process**

During/After experiences based on treatment decision (97) *(also represents the impact of the decision)*

Feelings about treatment decision (24) *(negative or positive)*

Impact of treatment decision (75) *(negative or positive)*

Process of making treatment decision (79) *(can involve others or not, can be complex or simple)*

Satisfaction with treatment decision made (83) *(satisfied or not satisfied)*

*(phase/stage of decision process = before, during, after) ←Re-dimensionalize above concepts into Rx decision into phases*

### **The Story (This story seems to be centered around the actual decision(s) that was/were made)**

#### **Chapter 4: Before the decision/Influences of decision being made**

The chapter would talk about factors leading up to a treatment decision being made:

-Symptoms, impact of fibroids on their life, socialization of healthcare, doctor recommendations, gynecological experiences, patient agency, doctor/patient relationship

#### **Chapter 5: Making the decision**

The chapter would talk about what factors mediate the decision(s) being made and the process and reasons for eventually making a decision:

-Patient agency, fibroid knowledge, gynecological experiences, doctor recommendations, intersectionality, doctor/patient relationship, social capital, fibroid conversations (with family, partners, doctors), struggle of weighing motherhood vs. treatment decision, social capital, and support (for decision making)

#### **Chapter 6: After the decision/Impact of decision-making process**

The chapter would talk about consequences or rewards of the treatment decision that they made:

-Level of satisfaction with their decision, gynecological experiences, patient agency (how care was managed), fibroid conversations, support, impact of treatment decision, feelings about treatment decision, and during/After experiences based on treatment decision



**Core Variable: Doctor/Patient Relationship (96 indicators in data)**

The doctor/patient relationship is self-explanatory and represents the relationship between the woman and her doctor she seeks or sought care from for her fibroids. The relationship can be positive or negative, trusting and comfortable or uncomfortable and lacking trust. Women may have specific feelings about this relationship. The relationship can be filled with various types of conversations about her and the treatment options available to her... etc.

**Questions for me:** Is this really a variable? Does it have dimension? –no, it’s all over the place, no theme in subcategories.

**Considerations for writing:**

**Type of relationship? (Needs to probably be re-categorized)**

Trust/comfort (16)

Conversations (39) (Need to dimensionalize/categorize)

Feelings about (13)

Negative (11) or Positive (24)

Caring (6)

Lack of understanding (6)

Partnership (17)

**The Story**

**Chapter 4: What influences what type of doctor/patient relationship that Black women have?**

The chapter would talk about factors that influence this relationship:

-gynecological experiences, symptoms, impact on life, socialization of healthcare, healthcare-seeking behaviors, doctor preference, intersecting identities

**Chapter 5: Doctor/patient dialogues and partnerships.**

The chapter would talk about they types of conversations that are had between her and doctor about fibroids, or lack there of. How and when do these conversations occur? Who has power in these conversations? How are partnerships formed between her and the doctor, if at all?

**Chapter 6: How does this relationship impact experiences with fibroids?**

The chapter would talk about consequences or rewards from the doctor/patient relationship:

-Women wanting more options, doctor preferences, doctor recommendations, patient agency, treatment decision for fibroids

### **Core Variable: Patient Agency (83 indicators in the data)**

Patient agency refers to whether or not Black women manage their own health, make informed treatment decisions, and essentially their empowerment as agents of their own health when it comes to the management and treatment of their fibroids.

**Questions for me:** Is this really a variable? Does it have dimension?

**Considerations for writing:** The context of Black women as patients is important in this narrative. Historical context already provided in proposal, but would need to add more about present day experiences.

### **Representations/methods/types of patient agency**

Management of care (40)

No (1)

Yes (35)

Patient researched on fibroids (20)

No (3)

Yes (12)

Recommendations for other women with fibroids (5)

### **The Story**

#### **Chapter 4: Who has patient agency? Why and when do they exercise this?**

The chapter would talk about factors that cause one to have or not have patient agency:

- Symptoms, impact of fibroids on their life, doctor recommendations, their doctor patient relationship
- Under what conditions does patient agency start or not start, and does it change over time?

#### **Chapter 5: How is patient agency exercised? What mediates it?**

The chapter would talk about strategies and mediators of patient agency:

*Strategies*- management of care, patient research, or recommendations to other women with fibroids. It is exercised through the doctor/patient relationship, experiences with the healthcare systems, and fibroid conversations.

*Mediators*- doctor recommendations, intersecting identities, socialization of healthcare, healthcare-seeking behaviors, medical mistrust, gynecological experiences.

#### **Chapter 6: What happens as a result of patient agency?**

The chapter would talk about consequences or rewards of patient agency:

- Patient agency impacts the treatment decision and process, it may affect their coping strategies, and influence the doctor/patient relationships